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Evaluation and synthesis of studies using qualitative methods of analysis



SWEDISH AGENCY FOR HEALTH TECHNOLOGY ASSESSMENT AND ASSESSMENT OF SOCIAL SERVICES



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Evaluation and synthesis of studies using qualitative methods of analysis

Investigations of such questions as quality of life are usually undertaken by means of quantitative research methods, in the form of questionnaire-based numerical rating scales. When the aim of a study is to achieve a deeper understanding of a person's subjective perception of – for example – quality of life, a person's individual perceptions, experiences, impressions and actions, then qualitative research methods may be more relevant. Such methods offer an understanding of associations from the individual's perspective. Some overlap of descriptions can occur, because the questions used in questionnaire-based rating instruments in quantitative research are usually derived from qualitative methods, for example, in the form of analysis of interviews. However, qualitative research discloses mainly new information. In this way the methods are complementary.

One example is a report from the Danish Health and Technology Assessment Council, investigating the potential benefit of follow-up for cancer patients, in which both quantitative and qualitative studies were evaluated [1]. The qualitative studies revealed that patients who have undergone treatment for cancer perceive that follow-up appointments enhance their quality of life, by offering reassurance and reaffirmation – and relief if re-examination is uneventful, i.e. no recurrence of disease. In the quantitative studies, the rating scales disclosed no differences between patients who had undergone follow-up and those who

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had not. The qualitative studies thus captured information which "fell into the cracks" between the questions of the quality of life rating scale.

SBU evaluates methods/interventions applied in health, medical and social care. Included in this evaluation is scrutiny of how the patient/client or their relatives perceive different aspects of care, such as experiences of undergoing treatment or diagnosis, experiences of receiving different interventions, or of living with different conditions. Therefore the focus here is on qualitative research, with special reference to perceptions of patient/clients.

In qualitative research, the results are not products of statistical processes or other quantitative methods. Qualitative research offers insights into social, emotional and experimental phenomena. The aim is to gain an impression, to achieve an understanding, to explore characteristics of various environments and cultures and to understand the relationship between various processes. Another feature of qualitative research methods is that the researcher also functions as an instrument for data collection. Most qualitative studies focus on a single characteristic or a small number of characteristics. The studies yield very detailed, in-depth knowledge which can give increased understanding of phenomena from a perspective that is not amenable to quantitative methods. Further information about the differences between quantitative and qualitative research is presented in Table 1.

Table 1 Comparison of		Quantitative research	Qualitative research
quantitative and qualitative research [2].	What is reality?	• Reality exists independently of a person's belief and interpretation and can be measured directly (positivism)	 There is an independent reality but it can be accessed only through human interpretation, which leads to multiple perspectives (interpretivism) Some qualitative researchers argue that there is no independent reality, only individual or shared social constructions
	Relationship between researcher and participant	• The researcher does not influence subject data. Objective research, free from the influence of external values is considered possible	 Although the researcher tries to be as neutral as possible, inevitably the researcher and the subject influence each other The data analysis is influenced by the researcher's values; does not allow objective research, free from external values
	Acquisition of knowledge	Primarily through deduction	 Induction and deduction at different stages of the research process
	Research questions	 How much? How many? Is there a statistical difference between? Is there a correlation? Which are the strongest predictors of? 	• What? • How? • Why?

	Quantitative research	Qualitative research	Table 1 continuec
Approach	 Reductionist Study design is predetermined Understanding of a phenomenon from the researcher's perspective Focus on objective measurement 	 Holistic Study design can be flexible, allowing exploration of ideas which emerge during the study Understanding of a phenomenon from the subject's perspective Focus on subjective meaning, understanding and process 	
Context	• The importance of the context varies but contextual factors are often eliminated in controlled experimental studies	 The context is important in formulating meanings and explanations The research is undertaken in natural settings 	
Research instrument	• Validated instrument, measure, rating scale or questionnaire	• The primary research instrument is the researcher	-
Sampling	 Random or probability sampling Representative of population Predetermined by power calculations 	 Purposeful or theoretical sampling Reflects the population's diversity Flexible enough to be propelled by emerging theory In the ideal case the size of the sample is determined by data saturation 	-
Data	• Numbers	• Words and images	-
Analysis	 Statistical analysis Variables are the units of analysis Analysis after collection of data 	 Non-statistical analysis Themes are the units of analysis Analysis and data collection can be undertaken concurrently 	-
Output	 Descriptive statistics Statistical evidence of correlation or difference between groups Prediction of the effect of independent variable on an outcome variable 	 Detailed "thick" description Classifications Typologies Understanding 	-
Generalisation	Based on probabilityInferential	RepresentationalInferentialTheoretical	-

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Qualitative research can be utilised to investigate a person's perceptions, experiences, histories and interpretation of a certain phenomenon. It is also of value for disclosing potential barriers to change in a system and a person's inclination/ disinclination to undergo change. The common denominator in qualitative research is that the researcher tries to reach an understanding and wants to create a general picture of the phenomenon under investigation and sometimes to generate a theory.

One topic of research which has evolved in recent years is the question of how care services are organised, i.e. organisational research. This question has become increasingly important as it has been recognised that the ways in which care is organised, supervised and delivered can influence how successfully a method/intervention can be introduced and applied in the health and social care services.

Applicability of the research results

In undertaking a systematic review, it is important to determine beforehand how the research results are to be applied. This decision influences the work process, particularly with respect to synthesis. The following are examples of ways in which qualitative research results can be applied.

A non-systematic approach to applying the results of qualitative studies is to use the results of one or more qualitative studies in the discussion, to interpret and support the results of quantitative studies. The aim is to improve understanding or to place the quantitative results in context.

An alternative is a formal synthesis of the qualitative results. A few years after quantitative meta-analysis was established as a method in social science research, a corresponding method was introduced for qualitative synthesis. The founders, Noblit and Hare, called this method of synthesis meta-ethnography. Since then various methods of synthesis with different names have been introduced, but the basic concept is often the same, that is, an overview is made of the qualitative results, separately or parallel with the quantitative synthesis [3]. The qualitative synthesis is used to interpret the results of the quantitative synthesis, or to answer questions which are not answered by the quantitative analysis [4]. This synthesis resembles the GRADE-system which is used for quantitative studies, in that data from different studies are synthesised per effect measure. For examples of qualitative synthesis, see section on "Synthesis".

Among the international organisations in health technology assessment (HTA), interest in evaluating qualitative research increased once it was recognised that HTA is not always concerned solely with effect. HTA also examines such issues as why and how methods/interventions function, ethical dilemmas, how patients and the public relate to a given method/intervention, and the demands imposed by it, in terms of knowledge and skills of both professionals and organisations. When a method/intervention is to be introduced, synthesis of qualitative studies in conjunction with HTA provides decision-makers with the best possible evidence-based foundation on which – for example – to assess patient- or client-related aspects¹. This foundation can also provide support for different priority groups at local, regional and national levels. Moreover, the launch of new, expensive and unnecessary studies can be avoided, i.e. further primary studies become redundant because the evidence is already available. This can – for example – avoid intruding on gravely ill patients with interviews, observations or questionnaires [5].

Transferability of research results

Qualitative research methods have been criticised for being too dependent on the context, to have inadequate numbers of subjects and for producing results that cannot be transferred or generalised. However, generalisability or transfera-

¹ The same naturally applies for assessments within social care.

bility can have two dimensions. On the one hand, quantitative studies require a large material to allow conclusions to be drawn as to how much, how often, how many, etc. On the other hand, in-depth studies, based on detailed investigations and analyses, are required to identify a phenomenon. In qualitative research the term transferability is also used. Transferability is a quality of the results, indicating whether the results can be extended to settings other than the one in which the study has been conducted.

Transferability of qualitative results may be regarded in several different ways. In a paper by Larsson [6], the following argument was presented with reference to the transferability of study results. An initial argument claimed that there is no need to transfer the results of an ideographic study (about concepts), because they are based on the logic that they comprise a unique part, which together with other parts, contributes to a pattern of the whole. Nor is transfer meaningful in "negative" cases which undermine the established universal truth, because there is then no universal agreement. These two arguments do not however, imply that the studies are not meaningful in their own right.

It is however possible to improve the potential for transferability. This can be done by including as great a variety as possible of cases, of the same phenomenon, in the study. The argument for maximising variation is that the transfer is made not from a specific case or category, but from a number of such cases. The variation in the study is expected then to exist in other relevant situations to which one wishes to transfer the results. This argument for transferability is not applicable to studies with insufficient participants, for example in small, interview-based studies.

Another argument focuses on context and similarities of context. The focus must then be on empirical knowledge rather than on theoretical assumptions. Because the similarity between contexts has to be assessed empirically after the study, the researcher must determine whether or not there is in fact similarity with other contexts. This also presupposes that it is the context which determines a phenomenon or pattern.

The final argument is based on the fact that qualitative research often produces interpretations, theoretical concepts or descriptions i.e. patterns or configurations, which can be recognised in the empirical world. Recognition of a pattern may be considered to be a variant of transferability, insofar as the pattern which emerges is recognised in new cases. The argument here is that transferability can be achieved when someone can understand different situations, processes or phenomena with the aid of the interpretations within the research. The problem with this argument is that it is based on the individual researcher's interpretation of a context and an underlying assumption about homogeneity within a specific context [6].

In summary it may be stated that qualitative research is often dependent on the context and that the reader must reflect thoroughly over the transferability of the results to other socio-cultural environments. This applies even when the study includes a discussion of how extensively the results can be generalised and how well they accord with those of previously published studies. It is up to the

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reader to assess the transferability of the results. This is facilitated if the study includes a discussion of how the results provide a theoretical understanding of relevance to several different situations. For example, a study which investigated patients' preferences with respect to palliative care could contribute theories on ethics and humanity in health and medical services and thus be relevant in other clinical settings. Transferability always has its limitations, however. Therefore the sampling strategy is an important precondition for the reader to determine the limits of transferability of the research results. This applies to all research, both that undertaken with quantitative methods and that undertaken using qualitative methods [7,8].

General comments on qualitative studies

Exa

Although the various qualitative research methods can have common characteristics, there is a variety of study approaches, based on different fields of knowledge within, for instance, philosophy (phenomenology, hermeneutics), anthropology (ethnography) and sociology (grounded theory). The choice of method is determined by the aim of the study and the chosen method thus provides the research with a basic framework for formulation of the questions to be explored, data collection, analysis and interpretation [9].

Table 2amples of qualitativeresearch methods.	Method	Description	Study examples within healthcare	Study examples within social care
	Grounded theory	Grounded theory is applied primarily to develop theories about human behaviour by analysing qualitative data. Hypotheses are formulated on specific information and specific conclusions are drawn from the hypotheses	A two-part study of the psychological effects of: 1) total edentulousness 2) rehabilitation in the form of fixed dentures (implant- retained bridges). The aim was to document how people adjust to life without any teeth, how they cope with removable dentures and how fixed dentures and how fixed dentures influence quality of life compared with removable dentures. The authors disclose three categories: "feeling different from others"; "being unsure"; and – after rehabilitation – "being my old self again". These three form the main category "change in self-image" [10]	The aim was to study the diversity of family environment characteristics and abuse experiences among homeless young adults. 28 homeless young adults. 28 homeless young adults. 28 homeless young adults. 20 males and 8 females) were interviewed in-depth The study findings are divided into the following themes: "intrafamilial abuse", "caregiver abuse", "rejection" and "deprecation by caregivers" [11]

Method	Description	Study examples within healthcare	Study examples within social care	Table 2 continued
Phenomenology	According to Edmund Husserl (1859–1938), phenomenology com- prises both theory and method, i.e. a scientific theoretical perspective and a method (with several variants). Phenomenology is concerned with how we give phenomena the meaning they have, how they appear in our consciousness and how our experiences of these influence our way of understanding the world (worldview)	Physiotherapists work with the body. The overall aim of the study was to develop a deeper understanding of how the physiotherapist can help people with difficulties to define pain and stress problems to regain their lost feeling of being comfortable with their bodies [11]	In this study the objective was to explore and describe the experience of loss among nurses working in a long-term residential care setting Semi-structured interviews were conducted with seven nurses. The authors found three main themes: "life's final journey", "family" and "professional carer." [13]	
Phenome- nography	The phenomenographic method has been developed for educa- tional research. Pheno- menography can be defined as the science of the different qualitative means by which people perceive aspects of their environment. The primary aim is to distinguish various aspects of the phenomenon. In phenomenography it is important to distinguish between "the way something is" and "the way something is perceived to be". The most common form of data collection is by interview	The aim of the study was to investigate how nurses in supervisory positions perceive oral health in general and the oral health of patients in particular [11]	This empirical study explores and describes the variation in how evidence-based practice (EBP) is understood in social work. 14 semi- structured interviews were conducted with politicians, managers and executive staff in three social welfare offices in Sweden The study concluded that EBP is understood in different ways described in the following categories: 1) fragmented, 2) discursive, 3) instrumental, 4) multifaceted and 5) critical [14]	
Pheno- meno- logical herme- neutics	Phenomenological hermeneutics focuses on interpretation of text, e.g. interviews. That which is interpreted is not the experiences themselves, but the text which comprises the descriptions constructed in the interviews. The researcher restructures the text to find the underlying implications. Parts which have points in common are collected into larger units. The focus is on lived experiences, not the person. The following steps are involved: narrative interviews, naive reading and structural analysis	A study was conducted to explore the decision- making process involved in becoming an egg donor. The aims were to investigate what motivated the women to donate and their experience of being potential egg donors. The study used interpretative interviews to collect the data. The interview method was selected in order to encourage the women to express their impressions directly after the first consultation, before the women had had time to process their impressions [12]	In this study ten foster parents from rural communities in the northeastern United States were asked to describe what it is like to parent faster children with specialised health care needs. An unstructured interview approach was used Themes identified were: 1) accessing medical care, 2) overwhelmed and unprepared, 3) decision making, 4) feeling isolated and 5) feeling stigmatised [16]	

Table 2 continued	Method	Description	Study examples within healthcare	Study examples within social care
	Ethno- graphy	The critical assumption underlying ethnographic research is that people who are together for a period of time always develop a group culture. Ethnographic research focuses on the culture in which people live. The primary method used in ethnography is observation (usually observation by participation)	The researcher studied patients who were afflicted with mental illness for the first time, in order to investigate how their life conditions were affected. This was done by experiencing and identifying procedures in mental health services in Copenhagen [13]	The purpose of the study was to describe the every- day work by case managers within a case management intervention, focusing on their experiences. Participant observations with field notes as well as a group interview and individual interviews with nine case managers were undertaken An overarching theme was found: challenging current professional identity. In addition three sub- themes were identified: 1) adjusting to familiar work in an unfamiliar role, 2) striving to improve the health system through a new role, 3) trust is vital to advocacy [18]
	Herme- neutics	Hermeneutics is concerned with interpretation and understanding. In an empirical study, the most important analytical instrument is in fact interpretation. The interpretations are presented not as truths between cause and effect but as new and hopefully, rewarding ways of understanding other emotional responses, motives behind actions, thought patterns and other human activities which create meanings	A hermeneutic approach can be appropriate for the study of an existential question. In this example the researcher investigated what it is like to have to go to an accident and emergency department for treatment. The researcher interviewed eleven patients and four close relatives [11]	This Norwegian study aimed at increasing the understanding of the nature and quality of relationships between persons with dementia, family carers, and profes- sional care givers and how these relationships in turn influenced personhood in people with dementia The study was based on ten cases. An interview- guide which was semi- structured, was used in interviews with profes- sional caregivers and family carers. During morning care or activities at a day care centre, field notes were taken after participant observation of interactions between persons with dementia and professional caregivers [19]

Method	Description	Study examples within healthcare	Study examples within social care	Table 2 continue
Qualitative analysis of content	Analysis of content usually means that the researcher, by repeated reading of a text, identifies units of meaning which are then coded. These are then sorted into categories by comparing the similarities and differences between the units of meaning. No material may be excluded on the grounds that there is no appropriate category. Nor may any material fall between two categories, or be allotted to more than one category [9]	In a study aimed at highlighting feelings of loneliness among very elderly people, 30 people aged between 85 and 103 years were interviewed. As feeling lonely can vary from individual to individual, and as qualitative analysis of content was applied to identify similarities and differences in a text, this method was considered appropriate for the purposes of the study [11]	Stakeholders' perceptions of various influences on foster children's health were studied with qualitative research methods. Semi- structured interviews were undertaken with focus groups consisting of foster children, foster parents and foster care professionals. The data gathered was analysed using qualitative content analysis [20]	
Action research	Action research is intended to solve specific problems within a programme, an organisation or a community. It is generally associated with actions which result in changes and development. The most striking feature of action research is that it is based on the participants and is interactive. This means that all participants, both researchers and people practically involved in the study work together	The aim of the study was to develop and introduce an appropriate model for mentoring health personnel in the corrective services sector [13]	The study aimed at answering the following questions: 1) how can the views of young people be taken into consideration when developing social work practice? 2) what preconceptions of young people do social workers bring to their work? and 3) how do these con- ceptualisations and views interact? A specific approach, a methodology, was described in the study. This approach allowed the questions to be tackled through a unifying framework of action research	
			The underlying idea was to bring out the opinions of young people with inside experience of social work and to present these to practising social workers, who subsequently were asked to change their practice accordingly	

Table 2 continued	Method	Description	Study examples within healthcare	Study examples within social care
	Narrative method	The narrative method is appropriate for appli- cation for improving knowledge about meanings and patterns in descriptions by people of themselves and their lives. There is no single narrative method of analysis, but several complementary methods, all of which are based on the basic philosophical and theoretical principle that human understanding has a narrative form	In a study investigating pathways out of substance abuse and homelessness from an action perspective, data were collected by narrative interviews with formerly homeless women. For analysis, the data, based on the narratives, were first categorised and then interpreted from narrative perspectives, such as meanings or patterns [11]	The objective of this study was to explore the effects of the foster care experience on foster parents' biological children. Children from eight families were interviewed and the data was analysed through narrative analysis [22]

For further reading on these research methods, see Appendix 1.

Sampling

The aim is to select a sample which will lead to an increased understanding of variations in the phenomenon to be studied. Within grounded *theory theoretical* sampling is used, i.e. there is no pre-study decision about which subjects or how many informants should be included in the study. The study begins with few subjects and as the analysis progresses more are rolled into the study in order to be able to inductively create a theory about the phenomenon in question. This usually results in a heterogeneous group of informants.

Another method of sampling is *purposeful sampling*, which involves different methods amenable to different types of study, depending on the aims and conditions of the study. For example, the following sampling methods may be applied [17,23].

Snowball or chain sampling, sociogram

This method is applied to find people who have lots of information, or critical cases. By asking a certain number of people who else should be interviewed, the snowball increases in bulk as new informants are found. Particularly important are those individuals identified by several informants as having useful information.

Maximum variation sampling

The aim is to capture and describe the variations of the phenomenon in different contexts. Problems may arise in understanding the phenomenon if the sample is too small and too heterogeneous because individual cases are so different from one another. Instead the focus is on finding information which highlights variations of the phenomenon and significant common patterns within the varying sample.

Extreme or deviant case sampling

This method focuses on people who have lots of information because they are unusual or special in some way.

Homogeneous samples

The aim of this method is to describe a specific subgroup in depth. Focus group interviews are often based on homogeneous sampling. People of similar back-ground and experience are selected to participate in focus group interviews on specific topics which affect them.

Convenience sampling

This is the least desirable sampling method. The researcher reasons that, as the sample is not large enough to produce transferable conclusions, then he/she can select informants who are readily accessible and inexpensive to study. As a sampling method, convenience sampling is neither meaningful nor strategic.

Methods of data collection

Various methods of data collection can be used in qualitative research (Table 3). The method depends on the topic to be studied. Interviews can be appropriate for the study of experiences (opinions, emotions, needs and desires), while observation is more appropriate for behavioural studies (interpersonal relationships, group dynamics, gender role patterns and so forth) [17,23].

Interviews can have various structures, e.g. open, semi- or fully structured. Interviews can also be conducted in different ways, for example an in-depth interview one-on-one, interviews with people in the street or focus group interviews.

Observations can be made with the researcher as a participant or as a nonparticipant. The people under observation can have varying degrees of awareness that they are being observed and what is being observed. Observations are documented with the aid of note-taking or video-recording.

Questionnaire investigations with open-ended questions.

Written material, e.g. diaries, minutes of meetings, descriptive reports, journals and literature.

The same methods of data collection can be used in the different qualitative research disciplines. The difference will then be in the way the material is analysed and interpreted when using different research methods.

Sample size

In qualitative research, there are no rules about what size a sample needs to be; instead this is generally determined by the need for information. A guiding principle in data collection is data saturation, i.e. the amount of collected data required for a specific study varies according to how rapidly the researcher considers that a stage has been reached where further data collection does not yield further knowledge – in other words, that saturation has been achieved. It is however, quite common to continue collecting further data, as a precaution. The number of informants required to reach saturation depends, for example, on the breadth of the issue under investigation. Investigation of a more broadly defined issue will probably require more informants before saturation is reached. Other modifying factors may include how well the informants can reflect on – for example – their experiences, how they communicate these reflections and how competent the researcher is in collecting data from informants or observations. The term "saturation" comes from grounded theory, but it is also applied in other qualitative methods/interventions [9].

Analysis

Because the researcher often undertakes the data collection, he or she also becomes a part of the analysis and this starts as early as during the process of data collection. There are various ways of analysing qualitative data. The method is often determined by the theoretical perspective or research methods on which the study is based. For further reading on research methods and analytical methods, see Appendix 1.

Table 3 nethods ction of		In-depth interviews	Focus groups	Observation	Documentary analysis
ata [2].	Key features	Individual interview in which the participant is encouraged to describe in depth his or her perspectives of a research topic	 Group discussion facilitated by a researcher/ moderator The groups comprise around 6–10 people The groups may occur naturally or comprise individuals recruited to the study Data are generated by participant interaction 	The researcher observes behaviour, events and interactions. Includes: • Participant observation (the researcher participates with the study subjects in order to experience the phenomenon personally) • Direct observation (the researcher observes the participants but remains independent)	The researcher studies the documents to explore their content and meaning
	Type of data	Generated	Generated	Naturally occurring	Naturally occurring

Examples of methods of collection of qualitative data [2].

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	In-depth interviews	Focus groups	Observation	Documentary analysis	Table 3 Examples of methods of collection of
Forms of data	Transcript of interview (verbatim)	Transcript of group discussion (verbatim)	Video recordingsTape recordingsField notes	Documents such as official reports, minutes of meetings, editorials, diaries, letters, magazines, posters, etc	qualitative data [2].
For use when	 The perceptions of the participants are important Complex processes or experiences are being explored Investigating beliefs, under- standings and interpretations of phenomena Investigating decision-making and motivation processes Studying confi- dential issues The sample is widely dispersed geographically 	 The perceptions of the participants are important Exploring how attitudes, know- ledge and beliefs arise and are challenged When studying social norms Creative thinking is required Participants feel that they have nothing to contribute Participants can feel confident discussing sensitive issues in a group of people with similar experiences 	 The natural setting is very important Comparing actual and reported behaviour Studying social order, communication, behaviour or interactions Investigating implicit aspects of behaviour that are taken for granted 	 Exploring dominant discourses, prevailing norms, explaining phenomena Comparing public and private accounts of events Doing historical research 	
Choice of data collec- tion method	Interviews are a good method for disclosing the participants' perspectives on a phenomenon, or for investigating beliefs, motivations or decision-making processes	 If there is an imbalance of power or status among the participants, caution is required Discussion of sensitive topics should be handled cautiously 	Observational methods are good if different aspects of the research topic are subconscious or taken for granted, or in cases where the participants are reluctant to discuss the topic openly	-	

Evaluation and synthesis of qualitative studies

Formulating a research question

In searching the literature for relevant quantitative studies for potential inclusion in an overview, it is usual to formulate a question and search policy according to the PICO-model, where P is for population, I for intervention, C for control and O for outcome measure. However, for formulating a research question to be explored in qualitative studies, the SPICE-model may be more appropriate (Table 4). S stands for setting, P for perspective, I for intervention, C for comparison and E for evaluation [24,25]. There are some parallels between SPICE and PICO. For example P in PICO corresponds with S and P in SPICE, and I in PICO correspond with C in SPICE. Moreover the O in PICO resembles the E in SPICE. Not all components are necessarily represented in every study and the model should be regarded more as a helpful guide for structuring a research question and for conducting a search of the literature.

Table 4 SPICE-model for

formulating a research question.

4 or	Setting	Perspective	Intervention	Comparison	Evaluation
a	Where?	For whom?	What?	Anything else?	What was found?
Ι.	The context of a study, for example a cultural group, a healthcare system or a district	The perspective which is disclosed by different values and attitudes	The phenomenon which is being studied	Comparison (not all studies have a comparative component)	Evaluation which includes both the process and an evaluation of the results

Example 1

Structure of a research question formulated according to SPICE.

a) *Question to be addressed:* How do the parents of children with cancer perceive their quality of life at home?

Setting	Perspective	Intervention	Comparison	Evaluation
Home	Parents of children with cancer	Childhood cancer	Not applicable	Perception of quality of life

b) *Question to be addressed:* What types of interventions to increase psychological and physical health among children in foster care are effective?

Setting	Perspective	Intervention	Comparison	Evaluation
Foster home care	Children in foster home care	Supportive interventions	Not applicable	Psychological and physical health

Searching the literature

Creating a search strategy to identify studies based on qualitative methods is in all major respects similar to that of creating search strategies to identify studies performed by quantitative research methods. It is imperative that the literature searches are systematically constructed and that they are reproducible.

An important difference to be borne in mind in formulating strategies to identify studies based on qualitative methods, in contrast to quantitative methods, is that there are discrepancies in the database indexing and/or the abstracts of the articles. A central database such as Medline (PubMed) does not provide a differentiated indexation of various research strategies intended to disclose the individual's subjective experiences, based on the way the

individual expresses them. Other obstacles are that the formulation of titles and abstracts can lead to difficulties in the search process. Important information is sometimes missing in cases where the authors have elected not to structure the abstract according to the model: aim – method – results – conclusions – key words. A search based on the words in the title is made more difficult because they may lack direct association with the question addressed by the article. The lack of such information can in turn result in the article not being indexed with any controlled key word (descriptor) which is related to that which is usually described as "qualitative research" or "qualitative studies". Because of the problems with indexing it is difficult to formulate searches which identify specific qualitative research methods.

Examples of other approaches to finding studies using qualitative research methods are the use of "Related Articles" in PubMed, by scrutinising reference lists or by citation searching [26–28].

Choice of database

The research question always determines the choice of database, regardless of the type of study in focus. Some of the central databases are PubMed, Embase, Cochrane Library, CINAHL and PsycINFO. It is sometimes necessary to search complementary databases, such as Sociological Abstracts. Alternatives are SocINDEX and Social Services Abstracts, which are broad databases in the fields of sociology and the social sciences. Another reason for searching these subject specific databases is that different databases have different principles for indexing. For the same reason, more general databases such as Academic Search Elite, the citation databases in Web of Science and also the Social Sciences Citation Index give other starting points for a search and the opportunity to find studies which are not registered in the major biomedical databases. Further support in the search process is to be found in platforms, such as Elsevier SciVerse. The content of the platform depends on which databases are subscribed to it. Databases which may be found here are ScienceDirect, the citation database Scopus and also PubMed, which is free and not an Elsevier database. SciVerse does simultaneous searches and counts the number of "hits" in the respective databases, which gives an overall picture of which databases best match different search words and search strings. Thus a platform can be a very good starting point for trial searches in general and in particular for studies which are more difficult to find. It can also yield unique subject "hits".

Starting from available reviews or syntheses

When starting a new literature search, the first step is to check whether there are already similar systematic reviews available on the subject. Already available reviews are important in project planning and therefore also for literature searches. Reviews can also be useful in planning and structuring search strategies. In "Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions", Andrew Booth discusses and presents several already available search strategies for systematic reviews, regardless of design. He has also developed a search string for specifically searching

what he calls "qualitative systematic reviews" i.e. systematic reviews in which qualitative studies are synthesised [29]:

qualitative systematic review^{*} OR (systematic review AND qualitative) OR evidence synthesis OR realist synthesis OR (qualitative AND synthesis) OR meta-synthesis^{*} OR meta synthesis OR metasynthesis OR meta-ethnograph^{*} OR metaethnograph OR meta ethnograph^{*} OR meta-study OR metastudy OR meta study

Search filters

A search filter or "hedge" is an aid designed to simplify searches for a certain study design, or specific aspects such as side effects or diagnoses. A filter is a search strategy which has been evaluated in terms of sensitivity and accuracy. Various filters are created and modified to suit different databases. The aim i.a. is to make searching for information more effective. Search strings usually comprise both controlled search words from the database thesaurus² and freetext words i.e. commonly occurring words in the database description of words forming i.a. the titles and abstracts of articles included in the database. The search filter is then combined with free-text words for the actual topic.

Several organisations are involved in developing and evaluating search filters, including those for searching for studies based on qualitative data. The Hedges Project at McMaster University in Canada has developed search filters for – among others – Medline, EMBASE, PsycINFO och CINAHL. At Centre for Reviews and Dissemination (CRD) in Great Britain there is a group of information specialists working on identifying and evaluating currently available filters. These filters are available at www.york.ac.uk/inst/crd/intertasc/qualitat.htm.

Searching with controlled search words

Although there are a number of search filters for "qualitative studies" there may be several reasons for deciding to create a search string. This may be because the filters are not adapted to the topic or database in question, or that the filter is obsolete because of changes made to the content or the means of indexing the database.

Databases which cover the research field, where studies based on qualitative data are common, offer as described earlier, more detailed indexation. For many years, CINAHL has had a number of useful controlled search words. Apart from the general term *Qualitative Studies*, there are also index words such as *Ethnographic Research, Ethnological Research, Phenomenological Research* and *Grounded Theory*. In Medline there are considerably fewer controlled subject words. The more comprehensive term *Qualitative Research* was not introduced into the MeSH-database until 2003. Also available are for example, *Nursing Methodology Research* and *Focus Groups*, which have been included in the MeSH-database since the 1990's.

² A thesaurus is a list of groups of similar or synonymous words and phrases, so-called descriptors or key words, which are used to characterise documents in a database.

A thesaurus is an aid which both changes and develops over time. New terms are added when new aspects of different research fields are developed, or when new terms begin to be used in research. Older index words are deleted or superseded. In order to systematically identify which specific index words are to be found in the different databases, data-specific thesauruses are used. In CINAHL with Full Text via EBSCO, the thesaurus is to be found under the heading *Cinahl Headings*. In this case *Research Methodology* provides a useful entry point for a better overview. In Medline (PubMed) it can be expedient to start with the *MeSH browser* or *MeSH database*. One can then select the overall heading *Research* or descend a few steps in the hierarchy to *Qualitative Research* and the term *Nursing Research*. In PsycINFO via EBSCO, a good starting point for identifying index words is to go to *Thesaurus* and then to *Methodology*.

Searching with free-text words

As in any other literature search, in searching for studies conducted by qualitative research method, thesaurus terms should be combined with free-text terms in order to disclose non-indexed studies. It is often preferable to limit the search to the fields *Title* and *Abstract* in order to reduce, to some extent, the irrelevant hits associated with free-text searching. Searching with free-text terms is particularly important in databases where the choice of thesaurus terms is limited; in this way the search will include different theoretical strategies which are common in this type of research.

Suggestions for search strategies in PubMed

The following are suggestions for search terms which can be used in designing various forms of search strategies:

"Qualitative Research" [MeSH] OR "Focus Groups" [MeSH] OR "Nursing Methodology Research" [MeSH] OR qualitative [Title/ Abstract]² OR "grounded theory" [Title/Abstract] OR ethnogra* [Title/ Abstract] OR ethnolog* [Title/Abstract] OR phenomenogra* [Title/ Abstract] OR phenomenolog* [Title/Abstract] OR hermeneutic* [Title/ Abstract] OR focus group* [Title/Abstract] OR field study [Title/Abstract] OR narrative* [Title/Abstract] OR lived experience* [Title/Abstract] OR life experience* [Title/Abstract]³

³ A term such as qualitative can result in far too many hits because the term is used in many different contexts. In certain searches it is necessary to specify:

qualitative study [Title/Abstract] OR qualitative research [Title/Abstract] OR qualitative descriptive study [Title/Abstract] OR qualitative data [Title/Abstract] OR qualitative content analysis [Title/Abstract] OR qualitative interview*[Title/Abstract] OR qualitative approach [Title/Abstract] OR qualitative analysis [Title/Abstract] OR qualitative design [Title/Abstract] OR qualitative exploration [Title/Abstract] etc.

Selection of literature

Two or more people independently scrutinise abstract lists from the literature searches. Studies considered relevant in terms of title and abstract are ordered in full-text. The full-text article is retrieved even if only one of the scrutinisers considers that full-text reading is warranted. The scrutinisers then decide independently whether the articles retrieved are relevant to the research question and meet any other inclusion criteria. The scrutinisers then compare their inclusion lists. If the lists are not in agreement, then together the scrutinisers discuss the papers and reach consensus as to whether or not the article should be included.

Quality assessment

The criteria applied to determine the scientific dependability of qualitative studies are in many aspects similar to those applied to quantitative studies. The description of the study should be easy for the reader to comprehend and the study should be logically constructed. It should be clear why the researcher has chosen to use a qualitative approach in order to generate and/or analyse data and justify the selection of a specific qualitative method. The research questions to be addressed should be well-defined. Sampling and setting should be relevant and clearly described. The methods section should be presented in detail so that the reader can determine whether the data collection and analytical methods seem to be adequate. The researcher should also present the relationship between the data and the results, how the analytical process has been conducted and whether there is a link with a specific theory. The results and their interpretation should be described logically and unambiguously. The researcher should also address the issue of transferability of the results, with respect to both sample and setting. The scientific quality will be greater if the reliability and dependability of the data are high and if any analytical problems are addressed, i.e. if interpretation has been verified and any problems have been managed appropriately [30-32]. A check-list can facilitate the process of scrutiny for quality assessment (Appendix 2).

With respect to the role of the researcher in a study, distance and objectivity are important criteria in quantitative research, whereas the researcher is often considerably more involved in qualitative studies. The researcher often has a role as an instrument in sampling, data collection and analysis and thus the role of the researcher and his understanding are important components in quality assessment of the study. The term "pre-understanding" implies the "baggage" which the researcher carries with him into a research project. Pre-understanding influences the researcher throughout the project, for example during data collection and data analysis. Pre-understanding includes the researcher's hypotheses, experiences, professional perspective and the theoretical frame of reference which the researcher brings to the start of the project. In general, pre-understanding is an important aspect of the researcher's motivation for undertaking research into a certain topic, but it can also restrict his ability to approach a project with openness and the potential to learn from the data collected. The researcher should strive to achieve an active, aware attitude to his pre-understanding. The discussion of the method should therefore include an account of

how he/she has managed his pre-understanding and a presentation of his role in the study [8].

One potentially confusing issue in descriptions of qualitative research is the terminology. In some scientific articles, terms which are related to quantitative research are used, for example credibility. In quantitative studies, credibility is usually based on the validity, reliability and generalisability of the results. Within the qualitative tradition other expressions are often used. Credibility refers to the credibility of the data collection and analysis. Dependability refers to whether the research is independent of the researcher and his/her perspective. It is also important to determine whether other researchers can confirm the findings presented by the researcher, i.e. confirmability and also assess the generalisability or transferability of the results to other situations. Today there is a lack of consensus as to which terms should be used and it is therefore important to be aware of the terms used in both types of research [8,33]. See Table 5 for assessment criteria of the scientific quality of a study conducted with qualitative research methods.

High quality	Moderate quality	Low quality	
Clearly described setting (context)			
Well-defined question to be addressed	Research question is ambiguous	Question to be addressed vaguely defined	
Well-described sampling process, data collection method, transcribing process and method of analysis	Some ambiguities in sampling process, data collection method, transcribing process and method of analysis	Sampling process, data col- lection method, transcribing process and method of analysis not clearly described	
Well-documented awareness of methodology	Some ambiguities regarding the awareness of methodology	Poorly documented awareness of methodology	
Systematic, stringent presentation of data	Ambiguous presentation of data	Presentation of data is not systematic	
Clearly demonstrates that interpretation is based on the data	Some ambiguity as to whether interpretation is based on the data	Unclear that interpretation is based on the data	
Includes a discussion of the trustworthiness and depend-ability of the interpretations	Some ambiguity as to the trustworthiness and depend-ability of the interpretations	Discussion whether the trustworthiness of the interpretation is poor or missing	
The results are presented in the context of previous research on the topic	Some ambiguity in presentation of the results in the context of previous research on the topic	Contextualising of the results in relation to previous research omitted or poorly developed	
Implications for clinical practice are well-formulated	Proposed implications for clinical practice are ambiguous	The implications for relevant clinical practice routines are not presented or unclear	

Table 5 Criteria

for assessment of scientific quality of a study conducted with qualitative research methods [34].

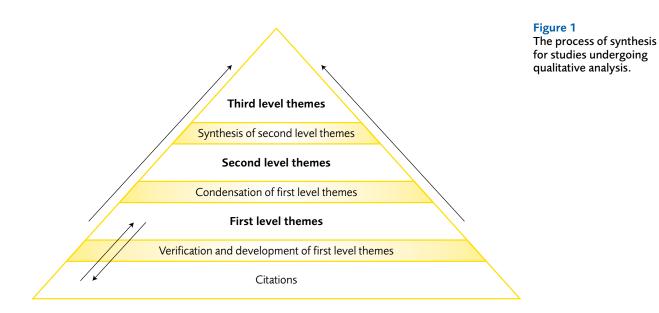
Synthesis

After the quality assessment process, the studies are tabulated (Table 2.4) and then stratified according to method/research design. In cases where the raw material comprises text which reflects what the informant has said, allocation to category should be exemplified by quotations. Other cases, for example observation studies or action research, require a presentation of how the categories in the synthesis have been formed, or if they are based on the original categories in the included studies. In synthesising the results of studies conducted according to different research methods, caution is required, and the choices made should be discussed and justified. Thereafter the synthesis is initiated, which means that the results from the different studies are combined to form new perspectives or views. The synthesis can be undertaken, for example, according to Howell Major and Savin-Baden, 2010 [35]. In the same way as for selection of studies, synthesis is undertaken by two (or more) people; initially each does an independent synthesis, which is then discussed by the pair or the group, until consensus is reached.

There are four stages in the synthesis (Figure 1):

- Studies which are included after quality assessment are screened in order to identify results in the form of themes (codes, categories, or subcategories). The themes should then be verified by citations (if available). Next, the studies are screened to identify those themes appearing in several studies. These themes are then condensed during the development of the *first level theme*.
- 2. Related *first level themes* are then distilled to form the *second level theme*. This is a complex and dynamic process where the themes are arranged and re-arranged several times until a clear second level theme emerges.
- 3. Related *second level themes* are finally synthesised to an overall *third level theme*. Important patterns and associations among the second level themes are interpreted and problematised. The process is repeated until third level themes are set.
- 4. A general assessment of the scientific basis is made. Thereafter evidencegraded results and conclusions are formulated [35,36].

The results from studies with a qualitative method of analysis cannot be merged according to GRADE (Chapter 10). The analytical process is however, similar to GRADE, where the individual themes could be regarded as outcomes. Just as the results per outcome are merged in GRADE, the results per theme are added together in the qualitative synthesis. Currently SBU is in the process of developing a method of merging results also from studies using qualitative methods of analysis [37,38].



The strength of the evidence in the results is assessed according to the following criteria:

There is scientific support – The identified studies are of adequate quality and relevance.

The scientific support is inadequate – The studies identified do not show adequate quality and relevance.

Evaluation of the strength of the evidence is undertaken by at least two people who have to reach consensus.

Example 2 Synthesis of patient participation: schizophrenia.

The following examples are taken from SBU reports within health care, but the same principle applies also when synthesising studies within social care.

The synthesis is presented in full (in Swedish) in the SBU report *Medicinal treatment* of psychosis/schizophrenia [34].

Question: How do patients, their relatives and nursing staff perceive other people's attitudes to the patients?

1. The studies selected for inclusion are read, in order to identify results in the form of themes (codes, categories or subcategories). These themes are then checked against any quotations in the text. The next step is to determine whether any themes recur in several studies. These are then condensed during the development of the first level theme.

Table 2.1 Examples of how the first level theme "both patients and their families feel excluded and alienated from several areas" has been expressed in the quotations.

Quotation with a specific focus	Structured quotation	Condensed quotation	Synthesised quotation	First level theme
"The media, as soon as something happens someone gets killed it was a mentally disturbed person who had schizophrenia"	I says that as soon as some- thing happens and someone is killed, the media gives the impression that it was committed by a mentally disturbed person with schizophrenia	I says that in reporting cases of violence with a fatal outcome, the media usually conveys an impression of a mentally ill perpetrator with schizo- phrenia	I notes that in the media, people with schizophrenia are blamed in cases of violent fatalities	Both patient and family feel excluded and alienated from a number of areas

I = Informant

2. Related first level themes are then merged to form second level themes. This is a complex and dynamic process whereby the themes are re-arranged several times until clear second level themes emerge, i.e. a number of first level themes is reduced to fewer second level themes.

Two of the first level themes comprise social isolation and loss:

- (1) Both patients and their families experience exclusion and alienation from several areas of activity
- (2) Restriction of their rights; public prejudice which can be counteracted

Example 2 continued

To some extent, all groups in the triad (patients, health personnel and family) feel that they are stigmatised and/or discriminated against, but particularly patients and their families. Having a mental illness is associated with weakness and lack of character, which is perceived both directly or indirectly.

"....you are the cause of the illness...".

"...it's all your fault..."

In the media, mental illness is often associated with violent or threatening behaviour; (patient):

"...The media, as soon as something happens...someone gets killed... it was a mentally disturbed person who had schizophrenia..."

3. Related second level themes are finally synthesised to a general third level theme. Important patterns and associations among the second level themes are interpreted and merged. Studies on which the synthesis is based are presented in a synthesis table, preferably in the form of a pyramid, see Figure 8.2.1.

See Table 8.2.2 for an example of a synthesis table for the third level theme "exclusion and stigma perceived by all three groups".

 Table 2.2 Third level theme: exclusion and stigma perceived by all three groups.

Second level theme	First level theme	Studies
Social isolation and loss	Both patients and their families feel excluded and alienated from several spheres of activity	Gonzales-Torres et al (2007)
	Restriction of rights Public prejudice which can be counteracted	Angermeyer et al (2003)
All the studies were of h	nigh quality	
	The example continue	es on the next page

Example 2 continued

4. The evidence-graded results are collated and formulated as a textual summary and in the form of tables.

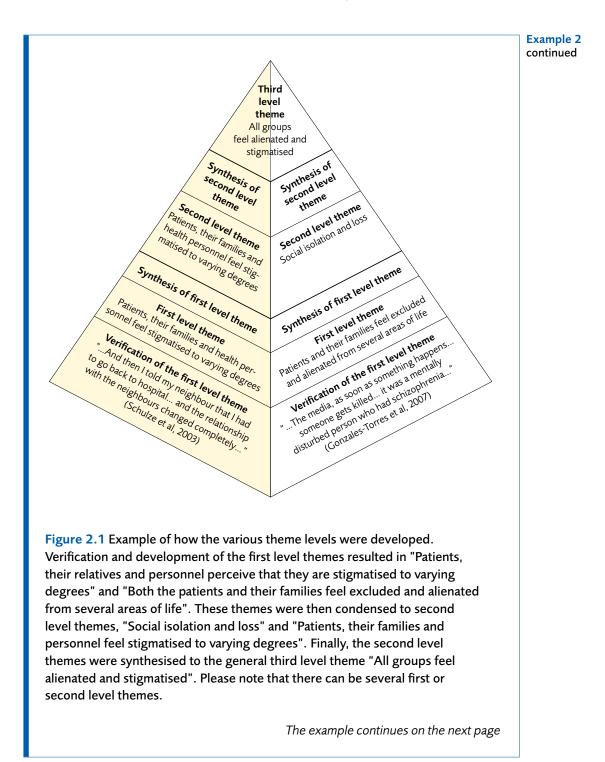
Table 2.3 shows the second level theme "social isolation and loss".

Third level theme: exclusion and stigma experienced by all groups

There is scientific support for the claim that people with schizophrenia feel discriminated against in several aspects of life and feel alienated. This also applies to family members and health personnel, however, to a lesser extent.

Table 2.3 Second level theme: Social isolation and loss.

Second level theme: Social isolation and loss	Country Study quality Number of studies (number of informants)	Description
First level theme Exclusion and alienation from several fields, both patients and their families Restriction of rights. Public prejudice which can be counteracted	Germany, Spain 2 studies of high quality 2 (140)	Patients and their families perceive that mental illness is degrading in itself and feel that they are stigmatised in several fields of life. They feel lonely and isolated from their surroundings. They describe such social losses as difficulty finding employment and discrimination in healthcare. The families of patients with schizo- phrenia also feel stigmatized by association. Discrimination is described at several levels. Better communication, support, training and guidance are examples of measures which could counteract stigmatising.
		The example continues on the next page



Example 2 continued

Table 2.4 Examples of tabulated study in a report.

Author Year Country	Material Analysis method	Informants
Gonzalez-Torres et al 2007 Spain	On stigma and discrimination Theoretical sampling	Patients (n=18, 9 females). Both long- and short-term illness
	Transcribed focus groups (3 groups with patients; 3 groups with family members)	duration. Family members (n=26, 19 females) related to various forms of illness duration
	Field notes. Qualitative analysis (Krueger/Casey)	

Results	Summary	Study quality Comments
6 categories of stigma experiences: Mental illness vs lack of will; Prejudice related to dangerousness; overprotection – infantilisation; daily social discrimination; discrimination in health care; descendants;	Patients and relatives describe a great variety of stigma and discrimination experiences in all areas of life, including health care. Isolation and avoidance are common reactions	High Publicising these experiences could reduce stigmatising and result in healthier reactions, favouring a better course of the illness
avoidance – social isolation Data from relatives were in 3 sets: Discrimination towards the patients witnessed by		Mainly women among the family members Unclear correspondence to average situation
relatives; discrimination suffered by the relatives; discrimination suffered by the relatives themselves and discrimination exerted by the relatives on the patients		No information on ethical approval is presented

Example 3 Synthesis of experience of edentulousness.

The full synthesis is presented in Swedish in the report "Tandförluster" by SBU [39].

Question to be addressed: How do people perceive loss of teeth and being edentulous?

1. The included studies are screened for results in the form of themes (codes, categories, or subcategories). The themes are then identified and verified by quotations (if plausible). Next, the studies are screened to identify those themes appearing in several studies. These themes are then condensed during the development of the first level theme.

Table 2.1 gives an example of how the first level theme, "sorrow and shame", is expressed in a quotation.

Table 3.1 An example of how the first level theme, "sorrow and shame", has been expressed in a quotation and condensed and synthesised to the second and third level themes [28].

Quotation with specific focus	Structured quotation	Condensed quotation	Synthesis	First level theme	Second level theme	Third level theme
"I've found when I'm speaking to people I tend to be looking at their teeth and thinking. What lovely teeth you've got. Silly. I know. I didn't do that before Here's me with these horrible false teeth"	The inform- ant says that when she talks to people she tends to look at their teeth and think: what lovely teeth you have. She didn't do that before And here is the inform- ant with these awful false teeth	These days when the inform- ant talks to other people she notices if they have beautiful teeth, in contrast to the informant's own ugly false teeth, dentures	Informant takes note if others have lovely teeth and compares them with the inform- ant's own ugly dentures	Sorrow and shame	Dimin- ished self- esteem	Loss of quality of life

Example 3 continued

2. Related first level themes are then distilled to form the second level theme. This is a complex and dynamic process where the themes are arranged and re-arranged several times until clear second level themes emerge, i.e. a number of first level themes are reduced to fewer second level themes.

Below are examples of the second level theme "diminished self-esteem".

Diminished self-esteem embraces three first level themes: the influence of loss of teeth on self-confidence, appearance and sorrow/shame. The edentulousness person perceives the condition as reducing them to the status of an amputee, no longer whole, but a lesser being. The diminished self-esteem can also lead them to doubt their sexual attractiveness.

"I've always been quite fit and that person, suddenly to find that person, that part of me, is going downhill."

"One feels somewhat misplaced, handicapped. Not human in a way."

The edentulous person lives with constant inner insecurity and fears that others may regard having no teeth or having bad teeth as a laughing matter. This can be described as a sort of oral hypersensitivity.

"If someone laughed, I thought they were laughing at me."

"I feel embarrassed to go to bed, you turn your back because I feel my partner will keep laughing, and so... your confidence is gone."

The change in appearance is perceived as premature ageing, one grieves for lost youth and it can become so unbearable that the edentulous person does not want to look in the mirror.

"Because a person with no teeth looks older. There is no way to say that they don't because they do, you know?"

Many people grieve over their lost teeth and are ashamed about their poor oral health.

"I've found when I'm speaking to people I tend to be looking at their teeth and thinking. What lovely teeth you've got. Silly. I know. I didn't do that before... Here's me with these horrible false teeth."

In contemporary Swedish society it is unusual for people to have gaps due to missing teeth, or poorly functioning removable dentures. The mouth and the teeth are perceived as sensitive, private areas which are not subjects for discussion and one does literally not want to "lose face" by being seen without teeth, even in front of one's closest family.

Example 3 continued

3. Related second level themes are finally synthesised to an overall third level theme. Important patterns and connections among the second level themes were interpreted and problematised. The process is repeated until third level themes are set.

See Table 3.2 for examples of tables of synthesis of the third level theme "loss of quality of life".

Table 3.2 Third level theme: loss of quality of life.

Second level theme	First level theme	Studies	
Diminished self-esteem	Effect on self-confidence	De Palma, De Souza e Silva, Fiske, Smith, Trulsson*	
	Appearance	De Palma, De Souza e Silva, Fiske, Smith, Trulsson*	
	Sorrow/shame	Fiske, Smith	
Lower social status	Social stigma	De Palma, Fiske, Smith, Trulsson*	
	Social competence	De Palma, Fiske, Smith, Trulsson*	
	Anxiety about being disclosed or unmasked	Fiske, Graham, Trulsson*	
	Taboo	Fiske	
Compromised function	Loss of function	De Palma, Fiske, Smith	
	Pain-impaired function	Trulsson*	
Managing loss	Adaptation	De Palma, Fiske, Graham, Trulsson*	
	Self-reproach	De Palma, Fiske, Graham, Smith	
	Making excuses	Trulsson*	

* Study of high quality. The other studies are of moderate quality.

4. A general assessment of the scientific basis is made and conclusions are formulated.

The example "diminished self-esteem" is described below. The summarising introductory running text applies to several second level themes. Table 3.3 shows the second level theme "diminished self-esteem".

Third level theme: loss of quality of life

There is scientific support for the fact that people who have lost all their teeth perceive diminished self-esteem, lower social status and poorer function. People deal with this loss in different ways.

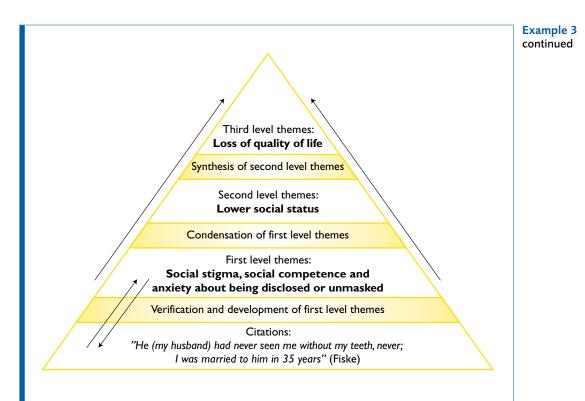


Figure 3.1 Example of how the different theme levels were developed. Verification and development of the first level theme resulted in "social stigma", "social competence" and "anxiety about being disclosed or unmasked". These were then condensed to the second level theme, "lower social status". Finally "lower social status" was synthesised with the other second level themes to the general third level theme "loss of quality of life".

Second level theme: Diminished self-esteem	Countries Study quality Number of studies (number of informants)	Description
First level theme Self-esteem, appearance and sorrow/shame	Brazil, England, Sweden 1 high quality, 4 moderate quality 5 (111)	Loss of all teeth is described as a traumatic life event, signalling that life has taken a downturn. The edentulous person is constantly insecure and fears that having no teeth or bad teeth will be considered by others to be a laughing matter. This can be described as a kind of oral hypersensitivity. There may also be self-reproach because they should have taken better care of their teeth. A person without teeth feels like a lesser being and this can also lead to perceived loss of sexual attractiveness. The change in appearance feels like premature ageing, there is grieving for lost youth and it can be so unbearable that edentulous people do not want to look in the mirror

Table 3.3 Second level theme: diminished self-esteem.

Example 3 continued

Table 3.4 Examples of tabulated studies in a report.

Author Year Country	Material method Analysis method	Informants	Results
Fiske 1998 United Kingdom	Transcribed in-depth interview Qualitative approach	50 individuals (14 m, 36 fm) x=69.9 years Toothless patients that seem well adapted to their dentures Dentures in 3 months–57 years \overline{x} =18.4 years	10 main themes: • bereavement • self-confidence • appearance • self-image • taboo • secrecy • prosthodontic privacy • behavioural change • premature ageing • lack of preparation
Trulsson 2002 Sweden	Transcribed in-depth interviews Grounded theory	18 individuals (8 m, 10 fm) 58–86 years x=71 years Edentulous patients treated at Brånemark Clinic	 3 categories with subcategories: Becoming an abnormal person: lack of dental awareness earlier in life feelings of shame and guilt physical pain Loss of confidence: physical suffering feelings of shame practical problems decreased attractiveness Becoming the person I once was: socially confident feeling attractive again good dental status feelings of gratitude

Summary	Study quality	Comments
Junnary	Study quanty	Comments
Loss of teeth like loss of any body part leads to a process of reactions: • to grieve • to cope with the acquired disability • to emotionally redefine the self	Moderate	The analysis is not fully described and could have been further developed This is an early qualitative study (1998) in this field and this may partly account for the methodological weaknesses
Description of changes in self-image starting with the subjects' increasingly deteriorating dental status, followed by a period of having to live with and cope with a denture and, finally, living with a fixed prosthesis Motivation underlying the decision to underge treatment with a fixed prosthesis seems to be a desire to restore not only oral function but also to regain earlier attractiveness, self-esteem and positive self-image	High	Relevant strategic selection of respondents The method is well described

Glossary

Category	An expression for a group, or codes which are similar
Code	A name or an identifying term for a specific section or expression of the data
Coding	The process by which the data are analysed and separated into sections which are given specific names
Condensing	The process in which a section of the text is abbreviated and made more manageable, while at the same time preserving the main content and ensuring that nothing important is lost
Constant comparison	Qualitative data analysis within grounded theory, whereby newly collected data are constantly compared with previously collected data
Core category	An integrative concept within grounded theory: a core category is related to all other categories which have been developed from the data
Credibility	The credibility of the results of a qualitative study and to what extent the reader can rely on the research and its results
Data	The information which the researcher collects through, for example, interviews, observations and documents
Data analysis	The process of reorganising and transforming the data, in order to explore the meanings of all the collected data. Relevant literature on the subject is also referred to
Dependability	To what extent the research is independent of the researcher and his/her perspectives
Focus group interview	A group of people, often with similar personalities or experiences, who are interviewed together in order to disclose their thoughts and opinions on a certain topic. Focus groups may also be used to disclose the way in which a certain group discusses various topics. An important aspect of this method is to pay particular attention to group dynamics
Informant	A participant in a study, who provides the researcher with information by means of interviews or observation
Member check	The researcher returns to the study participants for feedback, in order to ensure that the description and/or interpretation does in fact reflect their experiences
Narrative	A narrative can be a description of the participant's experiences in a study, or a researcher's reconstruction of their life or experience
Phenomenon	The main concept, events, attitudes, experiences or the occurrence of something that the study participants either experience or which emerges from the research
Saturation	When further data collection yields no new relevant data and when information has been received about all parts of all categories. Saturation in terms of analysis is achieved when no more analysis can be performed on existing data. Used in grounded theory
Theoretical sampling	Sampling conducted on the basis of relevant concepts which emerge during the conduct of the study and which is guided by the developing theory
Theory	A group of terms and theses which are interrelated, or a general principle which explains a phenomenon, sometimes presented in the form of a model
Transferability	To what extent the results of the study also apply to other environments and groups. In qualitative research the term transferability is often used instead of generalisability
Triangulation	The process of combining different research method, data collection methods, researchers or theoretical perspectives when a phenomenon is studied, in order to increase validity and reliability
Validity	To what extent the researcher's results reflect the aim of the study, represent reality and show integrity and quality. The term validity is different from that in quantitative studies. Terms such as "credibility" and "authenticity" are more common in qualitative research

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Appendix 1. General description of methods used in qualitative research

In recent years, qualitative research methods have developed and expanded to become an important alternative research approach. All qualitative research has a common foundation, but there are several different research approaches. The following are examples of some of the most common approaches.

Grounded theory

Grounded theory is used primarily to develop theories on people's behaviour by analysing qualitative data. The method encompasses both induction, in which hypotheses are formulated from specific data, and deduction, in which specific conclusions are drawn from hypotheses. It is important to minimise influences from existing theories and the researcher's pre-conceived ideas. The researcher must be open-minded with respect to what might emerge, both during collection and analysis of the data.

Within grounded theory, various methods of data collection can be applied, for example interviews, observations and documents (diaries, letters, etc). The method does not have to be determined from the beginning but can develop progressively. The aim is to collect plentiful data material, which should be

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subjected to systematic analysis. With respect to selection of participants, theoretical selection is used, which means that selection is steered by the previous analysis (ideas and concepts which emerge as relevant for the developing theory determine continued selection).

Data collection, analysis and generation of theory occur in parallel. When for example, an interview has been conducted, it is analysed immediately. In this way new ideas emerge which the researcher can apply in the next interview. The researcher constantly goes through his or her material in order to check that nothing has been overlooked.

Open coding means that the researcher goes through the material and gives every event or phenomenon a code which clarifies its content. Codes which have a common factor are grouped in categories. The coding procedures mean that the categories are related, either axially or horizontally, depending on the means of coding. Every category is specified in terms of the conditions which resulted in their formation. In selective coding, analysis leads to a main category, into which all the other categories can be integrated. Only after a main category has been established can a search be conducted of literature related to the central theme, or to several related themes. The main category is then analysed.

The constant comparative method is central to grounded theory and comprises asking questions and making comparisons. New and old codes are compared in order to distinguish similarities and differences.

During analysis, the researcher makes notes about questions, thoughts and preliminary interpretations of the association and the relationship between categories, so-called memos. The notes can contain for example, diagrams, mathematical formulae, tables and flow charts.

The researcher may not select data from the material in order to get it to fit a previously selected theory or concept. The theory which is developed is either substantive or formulaic. The substantive theory is developed for a specific, empirical area, for example a group of diseases. In contrast, formulaic theory is more general and can for example, include concepts which are not only associated with a specific diagnosis or a disease experience. Within grounded theory, theory development is regarded as a process without finality. A single study can therefore be a stage in the development of a more extensive theory [14,29].

The aim was to investigate how people with late complications of polio modify their daily activities. In order to form a heterogeneous group, the participants were selected to ensure variation in experience, gender, current age and age at onset of disease.

The informants were interviewed according to an interview guide with a list of topics to be covered in the interview. No prepared questions were used and the order of questions was modified to suit each interview. During the interviews the researcher made field notes. The interviews were complemented with a questionnaire to describe the informants. Using several data collection methods allows triangulation of data, i.e. combining data collected by several methods to ensure agreement. This leads to improved credibility and a deeper understanding of the results.

The transcribed interviews were read through to gain a grasp of the content as a whole. Then each row was read in the context of "what is happening/what does this mean?" The phenomena which emerged were coded (given a name). The next step was to group the coded material into categories and subcategories.

Because coping strategies were the central issue under investigation, the researcher focused on the categories which described this. For every strategy, questions such as when, where, how and why were formulated. With the aid of the responses to the questions, the subcategories emerged.

According to grounded theory, the material should be described in as few categories as possible. The researcher therefore undertook a further in-depth analysis of the main features of each category. This resulted in the strategies being summarised into six groups. Analysis and summary of the strategies resulted in a central phenomenon, the main category "maintaining a balance in daily activities now and in the future". The researcher continued to process the material in the same way and thus brought forth a further main category, with underlying categories and subcategories.

Example 1A Study using grounded theory as the research method [11].

Example 1B

Study within social care with grounded theory as the research method [11].

This qualitative study used data from a pilot study of a Social Enterprise Intervention (SEI); an extensive vocational training program with integrated clinical services for homeless youth. In-depth interviews were carried out with 28 homeless adolescents and young adults participating in the SEI study to explore their views on family environment characteristics and abuse experiences.

The informants, that were between 18 and 24 years of age (20 males, 8 females), were chosen by convenience sampling. During a period of one month, SEI staff spent 10 hours a week at the host agency in order to recruit participants into the SEI-program. Potential study participants were approached in a random order by the staff members in the central dayroom, and were asked whether they wanted to participate in the program. To select the youth two screening criteria were used. Firstly, during the month prior to the study, they had to have attended the agency at least twice a week. Secondly, they had to commit verbally to attend the program to receive vocational training for four months as well as business training for three months.

In order to analyse the transcripts from the in-depth interviews with the youth, a constant comparative method was used. In relation to family characteristics the following themes emerged: 'home instability', 'abandonment', and 'caregiver substance abuse'. Abuse-related subthemes that emerged included intrafamilial abuse, caregiver abuse, rejection, and deprecation by caregivers.

Grounded theory was the method of choice to interpret findings and to develop working hypotheses that could guide future studies of multi-type maltreatment among homeless youth.

Phenomenology

The focus in phenomenology lies in the individual's consciousness and lived experience. Two expressions are central: the life world (the world we are familiar with through our lived experience, which offers a means of understanding the world, without theoretical explanation) and intentionality/directionality (consciousness is always directed towards something; a perception is always a perception of something).

The researcher wants to get the informants to get in touch with their own experiences and formulate them in words. The researcher can use photography or film, request the informants to keep a diary, or describe events and situations which have affected them. Moreover, letters, drawings and paintings can be analysed.

It is important that the researcher can comprehend, envisage and imagine being in the informant's life world. It is also important to allow time for the informant to contact and reflect over his/her experiences. In order to capture the participants' continuing reflections, repeated interviews, seminars or focus groups may be used. Pre-understanding is the researcher's subjective research perspective. It is a requirement for reaching a viewpoint and developing new knowledge and understanding. However, it can also be an obstacle to seeing the new. It is therefore important for a researcher to reflect on his/her own subjectivity.

New knowledge is developed through alternately analysing the entire research material and the meaning and relationships of the individual parts. It is not possible to reduce understanding of the whole to the sum of its parts. Nor can the researcher claim to reach a definitive or "true" interpretation: but it must be stated that the interpretation which is presented is the most likely one [11].

The overall aim of the study was to develop an understanding of how physiotherapists can help people with non-specific pain and stress problems, to regain their corporeal identity.

A strategic selection was made of physiotherapists with long experience of the field in question. The researchers wanted a range of experience in order to have access to different aspects of how the physiotherapy treatment could be understood.

Each physiotherapist was filmed while treating a patient. The films were analysed and transcribed (written down, word for word). The material was used as a basis for the in-depth interviews which were conducted with each physiotherapist. By viewing every film over and over again new issues were successively disclosed.

During the in-depth interviews the film was first viewed as a whole and then in sequences while the physiotherapist was interviewed. Every interview was transcribed and a preliminary analysis was made before the next physiotherapist was interviewed. By this means new themes were developed which were deepened in dialogue with the physiotherapists during the course of the research process.

The transcribed interview material was analysed and processed in several stages. Initially the material was read through in order to gain an overall sense of the whole. Then the meaning units were delineated (meaning units are meanings which contain important information). Depending on content, they were coded into themes. The material was then read for a third time to specify the subthemes. Finally a flow chart was constructed to visualise the themes and subthemes. The data material was compiled into detailed descriptions of relevant data. In the next step, the researchers interpreted and highlighted the main ideas and meaning structures in the physiotherapists' understanding.

The next step was an analysis of the basic meanings in the physiotherapists' understanding. The units of meaning and the underlying assumptions were organised into a larger whole, with central themes and subthemes. The meaning of the material was then separated into three larger, more theoretical components.

The final stage in the analysis comprised a theoretical interpretation of the body, the being and the meaning. In order to be able to evaluate the relevance of the interpretation and the results from the perspective of everyday clinical practice, the results were discussed in a reference group.

Example 2A Study using phenomenology as the research method [11]. Example 2B

Study within social care with phenomenology as the research method [13].

In this Irish study the objective was to explore and describe the experience of loss among nurses working in a long-term residential care setting. A so called interpretative phenomenological analysis (IPA) approach was used with the aim of examining emotions and cognitions that underlie the descriptions of the subjective experiences.

IPA is phenomenological as it aim to seek the perspective of the individual's lived experience. The approach is also interpretative in that it acknowledges the personal beliefs and experiences of the researcher. Finally, the approach can be said to be idiographic in that it attempts to understand how a specific experimental phenomenon is understood from the perspective of the individual in a particular context.

The idiographic approach involves a detailed engagement with the transcript of each participant, and integration only occurs later in the analysis. In addition, IPA also requires the researcher to adopt a reflexive attitude. Hence, the first author noted personal reflections both before, immediately after, and one day after each interview. During data analysis these reflections revealed that some comments from the participants were difficult to shy away from.

The study sample consisted of nurses who all worked at a public long-term residential care setting in the West of Ireland. In response to a study information leaflet that was displayed in clinical areas inviting nurses to participate, seven nurses (five females, two males) volunteered to be interviewed. All of the seven nurses had worked in a long-term residential care setting for at least two years post-registration (both day and night duty). Five had worked with older people for over 15 years, whereas three of the nurses had a postgraduate qualification in gerontological nursing.

Semi-structured interviews, which were guided by an interview schedule, were used. Researches that uses the IPA approach often use such an interview schedule that facilitates the discussion of to the study relevant topics.

The authors found three main themes: 'life's final journey', 'family', and 'professional carer'. In conclusion the authors give their view on the implications of the results for clinical practice.

Phenomenography

Phenomenography is a method which was developed for pedagogical research. The method is intended to highlight individuals' various impressions of a phenomenon. The main aim is to differentiate various aspects of the phenomenon. It is important to differentiate between "the way something is" and "how something is perceived". The most common method of data collection is by interview [11].

The aim of the study was to investigate how senior nurses perceive the oral cavity

in general and the oral health of their patients in particular. In selecting the informants, the researchers focused on variation in gender, age, educational standard, years of experience and geographic distribution in order to gain as great a variation of perspectives as possible.

The interview questions were constructed with the aim of getting the informants to develop their thoughts about oral health and its importance and to capture their spontaneous opinions. The questions should not be leading, but open in character, for example "What does oral health mean to you?". The researcher was careful to put the questions in the same way to all the informants. Afterwards the interviews were transcribed word for word.

The researcher read the interviews several times in order to gain a sense of the whole. Then each interview was read in detail to identify statements which described the nurses' perceptions of oral health. These statements were compared for similarities and dissimilarities and grouped according to common features. After further comparison, reading and reflection, new dimensions were disclosed.

The perceptions were compiled in descriptive categories and were related to each other inasmuch as they contained different impressions of the same content.

That the same researcher conducted all the interviews strengthens the credibility of the data. However, there was a risk of misinterpretation, because the researcher did not personally transcribe the interviews. In order to avoid misinterpretation, the researcher read through the transcriptions at the same time as she listened to the tape recordings. Example 3A Study using phenomenography as a research

method [11].

Example 3B

Study within social care with phenomenography as the research method [14].

The aim of this empirical study was to explore and describe the variation in how evidence based practice (EBP) is understood within the field of social work. For this, a phenomenographic approach was chosen. How people understand a phenomenon is found in a limited number of qualitatively different ways. From a phenomenographic perspective; the aim is to reflect these understandings and hence not judge a statement as being right or wrong.

Study participants from three different levels and from three Swedish municipality welfare offices were recruited. Fourteen semi-structured interviews were held with eight males and six females. The length of which the present positions were held varied from one to twelve years, where staff had served the most years and politicians the fewest. The study participants were aged between 35 and 61 years. All of the managers and staff personnel had university degrees, whereas this was not the case for any of the politicians.

To get a deeper understanding of how the respondents understood the phenomenon, a combination of abstract and decontextualised questions were used together with encouragements to describe the phenomenon by giving examples of direct experiences and by visualising the consequences, referred to as 'situated examples'.

Subsequently, a phenomenographic analysis procedure was performed in accordance with the seven steps described by Dahlgren and Fallsberg (1991); familiarization, consolidation, comparison, grouping, articulation, labelling, and contrasting. The analysis resulted in five qualitative different understandings of EBP described by the following categories: 1) fragmented, 2) discursive, 3) instrumental, 4) multifaceted and 5) critical.

The authors concluded that it is important to acknowledge the different ways in which EBP is understood in order to create a supportive atmosphere in which EBP can thrive. In order to accomplish a social work practice that is beneficial for the clients various sources of knowledge need to be utilized; both research-based and practice-based knowledge.

Phenomenological hermeneutics

Phenomenological hermeneutics focuses on interpretation of interviews as text. What are interpreted are not the actual experiences but the text which comprises the descriptions constructed in the interviews. The researcher restructures the text in order to find deeper implications. Tangential parts are merged into larger units. The focus of attention is lived experiences, not the individual.

The strategy is based on the following method stages:

• Narrative interviews – a conversation in which the informant describes freely and reflects on lived experience and the interviewer and informant together bring out the implications in the phenomenon which is to be studied

- Naïve reading an initial superficial interpretation which captures a feeling of the whole
- Structural analyses investigation of the text intended to explain what it says; as a text can have several dimensions, more than one structural analysis may be necessary
- Comparison and interpretation of the whole critical reflection of the authors' pre-understanding, the naïve reading and structural analyses in order to reach a comprehensive understanding of the text.

In this study the researchers wanted to investigate the decision-making processes involved in egg donation. The aim was to investigate both the women's motivation for donating eggs and their experiences of being potential egg donors. The type of egg donation investigated in the study is so-called "egg sharing", which means that a donor who can produce eggs, but needs in vitro fertilisation, will be offered certain benefits, such as reduced waiting time or cheaper fertility treatment, if she is also prepared to donate eggs to a woman who is unable to produce eggs herself.

An opportunistic selection was made at a fertility clinic in the United Kingdom between October 1999 and June 2000. Interviews based on open questions were then conducted with eleven potential egg donors immediately after their introductory consultation at the fertility clinic, before the women had time to process their impressions. The interviews lasted about 45 minutes and were then transcribed word for word prior to analysis.

The analysis resulted in six themes on donating eggs. The motives for egg donation were multidimensional and all interrelated. The author drew the conclusion that egg donation can be seen as a symbol of hope. The author makes clear i.a. that egg donation is not to be regarded as an altruistic action, but as a link in an overwhelming desire to have children, in a system hampered by lack of resources.

Example 4A Study using phenomenological hermeneutics as the research method [12].

Example 4b

Study within social care with hermeneutic phenomenology as the research method [16].

In this American study the author aimed to explore the experience of foster parents caring for children with special health care needs who live in rural communities and remote areas in North-eastern United States. The study purpose was to compose a vivid description of the experience, in order for nurses to get a better understanding of what kind of problems foster parents of children with special health care needs who live in rural areas are faced by. The research question for this study was: What is the lived experience of foster parenting a child with special needs in a rural community? What is the essence of the experience?

As hermeneutic phenomenology is an approach that can be used to describe lived experience and which requires that descriptive and interpretive processes are merged, van Manen's methodological approach for a phenomenological inquiry was chosen. To recruit study participants, purposive sampling using criterion, as well as snowball techniques were used. The essential criterion to participate in the study was that of parenting foster children with special health care needs for at least six months. Ten participant were recruited, ranging from 24 to 66 years of age.

An unstructured interview strategy that was guided by one broad question, "what is it like to be a foster parent to name of child?" was chosen. Probes and open-ended clarifying questions were also integrated in the interviews. A circuitous process was used for data analysis in which reflection was initiated with the first interview, and it was subsequently continued in parallel with the data collection. It also included reading of transcripts multiple times and listening to audiotapes.

The data analysis revealed that the concerns that the foster parents have are related to accessing medical care and decision making. The parents expressed feelings of being overwhelmed and unprepared, isolated, and stigmatized.

Qualitative content analysis

Content analysis usually means that by repeated reading of a text the researcher identifies meaning units, which are then coded. These are then sorted into categories by comparing and contrasting the similarities and dissimilarities of the meaning units. No material may be excluded due to there not being an appropriate category. Nor may any material fall between two categories or be placed in more than one category [11].

With the aid of content analysis, the researcher can draw conclusions based on the data and its context; where the aim is, for example, to increase knowledge, provide new insights, or disclose facts. The aim is to achieve a detailed and extensive description of a phenomenon. Content analysis is common in, for instance, nursing, psychiatry, geriatrics and public health research. Written, verbal or visual communication may be analysed.

In a study of loneliness experienced by the very elderly, 30 people aged between 85 and 103 were interviewed. Because the experience of loneliness can vary from individual to individual, and because qualitative content analysis is appropriate for inductive thematisation of data, this strategy was considered suitable for the purpose of the study. The informants were identified through the electoral rolls; those who were invited to participate belonged to one of the following age groups: 85 years, 90 years or 95 and over. They lived in a geographically defined area. Thematic interviews were conducted and the introductory question concerned what it was like to be old. Apart from this question, questions were asked about the following themes; loneliness, the aging body, important life events, experience of solace and experience of meaning (meaningful events). The interviews were conducted in the participants' homes by four researchers, all with experience of working with the elderly.

The analysis was undertaken by two of the researchers. Initially, the entire text was read, in order to gain a sense of the whole. Then the researchers together reflected over the main content of the texts. The text was then divided into two domains, limitations and possibilities. Meaning units were then identified, condensed, abstracted and labelled with a code. The codes were then compared and categorised into ten categories. Thereafter a theme was formulated, based on the text as a whole, the content of the ten categories and the researchers' sense of what underlay the content. The development of a theme can be regarded as a process which is ongoing throughout the analytical procedures and which represents a summary result of the study.

Example 5A

Study using content analysis as the research method [11].

Example 5B

Study within social care with content analysis as the research method [20].

The purpose of this Hawaiian study was to explore varying influences on foster children's health and what support that is needed for the foster children in order for them to achieve optimal health. The researchers chose to use focus group interviews with semi-structured questions and content analysis as the method for data collection and data analysis.

In total, seven focus groups were formed. Out of these seven, five groups were made up of former foster children (32 adolescents in total). In addition, one group consisted of six foster parents, and a final group of ten foster care professionals was also formed.

An advisory board generated a similar set of questions for each stakeholder group. Each focus group interview started with a general question designed to address the participants' perception of how a child's mind and body were affected by the foster care experience and what positive and negative aspects of foster care that might influence the physical and mental health of foster children. The interviews were subsequently transcribed and analysed using Krippendorff's recommended procedures for content analysis.

The transcribed data was coded following an inductive and interpretive process that involved constant comparison techniques, searching for recurring themes, clustering, and development of mutually exclusive defined categories. To finish of the analysis, an interpretation of the meaning of the data, within a theoretically grounded framework was carried out.

The themes that emerged from this analysis focused primarily on the mental health of the foster children; including difficulties with perceiving oneself as being different; the need for coping strategies; problems encountered with the foster care system itself; transitioning between foster homes; and finally the need for medical homes. The stakeholder groups recognised the necessity of mutual support for one another. They also proposed potential solutions for addressing concerns.

Ethnography

The assumptions which govern ethnographic research are that every group of humans who live together for a period of time will develop a culture of its own. Ethnographic research focuses on the culture in which a person lives. The primary method applied in ethnography is observation according to the anthropological tradition. It requires intensive field work, in which the researcher gains a deep insight into the culture in question.

Modern anthropologists use ethnographic methods to study modern society and social problems, for example substance abuse. Ethnographers use methods for participant observation and field work. However, what distinguishes the method is that interpretation and application of the findings occur in a cultural perspective [13].

The researcher studied patients who had been afflicted by mental illness for the first time, in order to investigate how their life situation had been affected. This was done by experiencing and identifying processes in the mental health care system in Copenhagen, Denmark. The researchers participated actively in nursing staff meetings. Through informal discussions the researcher gathered information about their backgrounds. The nursing staff themselves wrote down their thoughts and observations. The researcher kept a diary and in this way could deal with his experiences and preserve a critical attitude to his research. As the researcher did not share the patients' experiences it was difficult to study the question from their perspective: therefore the researcher conducted interviews with fifteen patients. The interviews were recorded and then transcribed.

Each patient was interviewed five times over a period of two and a half years. The final interview was conducted six months after completion of treatment. Thus the researcher could both modify questions according to the patient's treatment phase and relate topics which arose during an interview with previous events.

The researcher sent out questionnaires to patients and their relatives and also conducted focus group interviews, with questions about the treatment and the support they felt that they received from the nursing staff. The nursing staff wrote about their experiences and also participated in the focus groups. Moreover, the researcher was an observer at meetings between patients and their healthcare providers and also attended meetings of the therapy groups. All collected material was transcribed, coded and compared, over time and between patients. By this means the researcher was able to identify various structures and processes within mental health care.

Example 6A

Study using ethnography as the research method [13].

Example 6b

Study within social care with ethnography as the research method [18].

This Swedish study explored the everyday work of Case Managers for older persons with multi-morbidity with the aim of describing the case managers' experiences of the Case Management intervention to better understand and contribute to the advancement of Case Management. To do so, an ethnographic approach was chosen, including individual interviews with nine case managers, a group interview and participant observations with field notes. Purposeful sampling was used when selecting the participants of the study. A thematic analysis was conducted of the interviews (that had been recorded and transcribed verbatim.)

As a research method, ethnography is characterized by the researcher's role as an instrument, and using observation and data collection, which takes place in the participants' normal environment, and that includes different sources, i.e. data triangulation. The ethnographic approach lets the researcher become part of the specific context of the study.

This study followed the principles of focused ethnography, which is an interpretive approach opening up for an in-depth study of experiences from both the perspective of the inside view of the study participants as well as the outside view of the researcher.

The authors identified an overarching theme in the data; "challenging current professional identity". Under this theme, they further identified three sub-themes, namely: 1) Adjusting to familiar work in an unfamiliar role, 2) Striving to improve the health system through a new role, and 3) Trust is vital to advocacy.

It was concluded by the authors that the findings of the study shows the complexity of Case Management for older persons with complex health needs, seen from the perspective of the case managers, describing how their daily work challenges their professional identity.

Hermeneutics

Hermeneutics is about interpretation and understanding. In an empirical study, the most important instrument for analysis is interpretation. Interpretations are not presented as the truth between cause and effect, but as new and hopefully rewarding ways of understanding emotional responses, motives, actions, thought patterns and other meaningful human activities.

The aim of hermeneutic interpretation is to gain a relevant, mutual understanding of the meaning of a text. Hermeneutics highlights the dialogue which creates the interview texts which are to be interpreted, and clarifies the process by which the interview texts are interpreted. This process can be regarded as a dialogue with the text.

The hermeneutic circle is typical for interpretation of meaning. Interpretation develops in a circular movement between the researcher's understanding and the collected material. It leads to new understanding which will become pre-understanding in future interpretative strategies. Another term for the hermeneutic circle is the hermeneutic spiral, to signify that it is not possible

to revert to a previous point. Understanding is deepened all the time. The hermeneutic process of text interpretation is in principle never ending, but in practice it ceases when a reasonable meaning is arrived at, a relevant uniform meaning without inner contradictions.

By interviewing patients and their relatives the researcher investigated what it was like to seek care at a hospital emergency department. When all interviews had been completed, the researcher transcribed the material and compared it with his/her own pre-understanding. The reading gave an initial sense of the meaning of the material.

The material was then sorted into themes and subthemes, which the researcher compared with the initial, preliminary picture. Each subtheme was withdrawn from its theme to be compared with the other subthemes. Tangential subthemes formed a basis for partial interpretation. In order to validate the partial interpretations, the researcher checked them against the data. The researcher tested various interpretations and constantly referred back to the data in order to determine which interpretation seemed most plausible in relation to the aim of the study.

In this manner, eight partial interpretations were developed. An example of a theme is: "high medical prioritising increases satisfaction with the care provided" and "socially weak groups find it hard to be heard". The partial interpretations were compared with each other and associated interpretations were grouped together as larger units. This led to three main strands: "to uphold dignity by directly or indirectly challenging the attitudes of the healthcare providers", "to maintain one's dignity by directing one's disappointment elsewhere" and "to maintain one's dignity by being a 'good patient'".

Finally the researcher formulated a main interpretation which highlighted the underlying pattern of the entire material. The main interpretation was validated in that it explained all the partial interpretations. Example 7A Study using hermeneutics as the research method [11]. Example 7B

Study within social care with hermeneutics as the research method [19].

A study on the influence of relationships on personhood in dementia care was conducted in Norway in 2013 and aimed at increasing the understanding of the nature and quality of relationships between persons with dementia, family carers, and professional care givers as well as how these relationships influenced personhood in people with dementia. Personhood can be understood as increasingly concealed rather than lost in dementia.

The hermeneutical design in this study was based on ten cases, where each case was made up of a triad: the person with dementia, the family carer and the professional caregiver. To participate in the study, persons with dementia had to be: 67 years or older, diagnosed with dementia, have a Clinical Dementia Rating score of 2 (ie. Moderate dementia) and finally, be able to communicate verbally.

In the interviews with family carers and professional caregivers, a semi-structured interview guide was used. Participant observation of interactions between professional caregivers and persons with dementia were conducted during morning care or activities at a day care centre and field notes were taken. Data analysis was conducted in two steps, first an inductive analysis with an interpretive approach and secondly a deductive analysis that applied a theoretical framework for person-centred care.

The study revealed that there were three relationships that diminished personhood: unprofessional relationships between caregivers and persons with dementia, taskcentred relationships and reluctant helping relationships between family carers and persons with dementia. Contrary, the relationships that sustained personhood were professional relationships between caregivers and persons with dementia and close emotional bonds between family carers and persons with dementia.

Action research

The aim of action research is to solve specific problems within for example, an organisation or a community. In general, action research is associated with actions which lead to change and development. The most obvious feature of action research is the participant-based and interactive approach. This means that all participants, both researchers and staff of the organisation in question, work together. They contribute to the planning and conduct of the study. Thus the difference between research and action can be indistinct. The research methods tend to be less systematic, more informal and specific to the question, the people or the organisation under investigation.

Action research can be applied in various situations, with many different participants and in different environments. Today it is used increasingly in health-care and nursing to stimulate and develop various activities. Within research in health and medical care, action research is described in two different ways: as a means of conducting a study and as a study of the actual research process. These two can complement each other.

Classical action research is conducted cyclically in four stages: 1) planning based on thoughts and experiences, 2) the planned intervention is carried out,

3) the intervention is monitored by field observations and data collection and 4) the results are subjected to reflection, planning and evaluation and monitoring, which leads to new questions, which in turn lead to new interventions. It may be a thought or idea which originates within a personnel group. The thought is brought to the attention of a researcher who can participate in the process of change and investigate its effects on those who participate in the study. Regardless of the structure used, the people with a common desire to solve a problem or improve a situation are always at the centre of the process.

The advantage of action research is primarily the potential to conduct research in a practical environment, where both the researcher and the participants are active during the research process. Another advantage of action research is that it critically and openly scrutinises established practical routines, with the aim of improvement, development and new understanding. This co-operative approach enhances both practice and knowledge.

The aim was to produce and introduce a suitable model for guidance of care providers within corrective services. Initially there was marked opposition on the part of the care providers who felt they were being under surveillance, and were uncertain as to what the researchers intended to do with the information they collected. The researchers were therefore careful to clarify the aim of the project and their own roles within the group.

Five institutions participated in the project and appropriate co-workers were suggested as supervisors. Background information about the proposed supervisors was

collected by means of a questionnaire. The potential supervisors were then interviewed. A semi-structured interview technique was used, which meant that all interviews contained the same questions in the same order, but different follow-up questions were allowed.

The researchers were constantly aware of their own roles in the project and therefore worked together with the participants. With the three themes as a basis, the current situation was discussed and the consequences of introducing change were identified. Together, recommendations were developed for introduction of supervisors and the continuation of work within the caregivers' working group. Example 8A

Study using action research as the research method [13]. Example 8B Study within social care with action research as the research method [21].

Through action research, this study aims at answering three questions: How can the views of young people be taken into consideration when developing social work practice? What preconceptions of young people do social workers bring to their work? and finally how these conceptualisations and views interact?

The research took place in Iceland where the author worked directly with social work practitioners, examining the ways in which social workers conceptualize childhood and children and what this means for developing social work practice. The action research approach in this case also included engaging young people, who had interacted with social services, as research consultants. The aim was to get the opinions of young people with inside experience of social work and to present these to practicing social workers, who following this were asked to change their practice accordingly.

In the study, this approach is evaluated, with a focus on its usefulness for the development of social work practice but also as a method of generating new knowledge.

A major criticism of educationally based action research is that the credibility of the research process and the results will be negatively affected when the action researcher has the dual roles of researcher and educator. Because the research is conducted within a specific operative unit, it is difficult to transfer the results to other operative units.

Moreover action research is occasionally criticised for lack of development of theory and poor documentation of the research process [13].

Action research compared with quality development

Action research is often compared with quality development/quality assurance but there are several differences between these two methods, some of which we describe below.

Action research is usually initiated in response to a mutual problem which has been identified by a social group. The problem may be unclear and vague and change during the cycle, so that what was considered to be the problem in the beginning may be a quite different problem at the end. In quality assurance however, the problem is usually clearly defined and remains in focus during the whole process. In the planning phase, action research is based on a critically aware action while this stage of quality assurance comprises supervision and collection of data.

The results of a quality assurance project can either show improved methods of comparison or improved quality of a service. Quality assurance tends to result in improved standardised work routines within an organisation. The results of action research contribute to development of theory, either new theories or further development of an existing theory. In general, action research leads

primarily to improved working conditions and social conditions for the members of the group.

For action research to be considered successful, both interventions and development of knowledge are necessary. In quality assurance, the cycles may be static over time and need not necessarily include any interventions. In general, quality assurance has a much more rigid structure for completion of the project. In contrast, action research is flexible and allows continuous overhaul.

The narrative method

The narrative method is suitable for use when the aim is to increase knowledge about meanings and patterns in people's descriptions of themselves and their lives. There is no individual single narrative working method, but several complementary methods which are all based on the philosophical and theoretical foundation that human understanding has a narrative form. Some examples of narrative data analysis are presented here [11].

The whole is maintained in the narrative

The researcher tries to discern what characterises the narrative as a whole. In a study on retirement, with special reference to changes in daily activities and patterns of activity, twelve people were interviewed three times. The interviews comprised open questions, such as "Describe what an average day is like for you these days". The method of analysis was to retain the description as a whole and analyse basic narrative characteristics, such as direction, structure, plots and turning points. The results of the analysis disclosed that differences in structure were the most pronounced feature of the narrative.

Categorise first and then interpret on the basis of narrative starting points

In the initial step the material is analysed and systematised with the aid of a qualitative method for building categories and themes, for example the constant comparative method or qualitative content analysis. The data material is then categorised into main and subcategories. Thereafter the categories are interpreted according to narrative theory. The categories are placed in a theoretical frame of reference and form a whole.

Understanding events from a narrative perspective

This method can be used to understand both concrete events and different processes. For example one can investigate what happens in a treatment situation by trying to understand if/how isolated events can be associated with and integrated into the larger life story for the client. Several ethnographic studies of treatment situations involving occupational therapy rehabilitation have used the narrative strategy as a basis for understanding.

Example 9A Study using the narrative method as a research method [11].

In a study investigating pathways out of substance abuse and homelessness from an activity perspective, data were collected by means of narrative interviews with two formerly homeless women. The interview guide comprised open questions in order to capture the informants' stories. The researcher used follow-up questions to encourage the narrator and to ensure that all topics listed in the interview guide were covered.

The analysis began with the aid of the constant comparative method. The data were analysed in different stages and then compared with the transcribed interview. Thereafter the material was interpreted on the basis of the narrative theory, which means that the material was read several times, in order to gain an overall sense of the whole. The analysis was then conducted in the following four steps.

In the first step, all the material was coded on the basis of the interview text. The codes were allotted to categories. For example, the codes "social contacts outside the narcotics gang" and "narcotics as our little secret" were allotted to the category "double life". Step two comprised comparison of codes and categories, both with each other and with the original material, in order to identify overarching patterns which could intertwine codes and categories to form new themes. Each interview was thematised separately.

In the third step the interviews were combined by comparing all themes, categories and codes, both with each other and with the original data. With the aid of this comparative process, themes common to both interviews were identified; for example "homelessness is a pattern of activity". In order to gain an impression of the overarching coherence in the informants' descriptions, the mutual themes were interpreted as the final step in the analysis.

Example 9B

Study within social care with narrative method as the research method [22].

The aim of this study was to explore the effects of the foster care experience on foster parents' biological children. The author describes and discusses the losses experienced by the children of foster parents. Eight families, all from the same agency in central Canada had experience of having fostered for at least three years, both with child welfare and probation placements. The children from these families (one youth per family) were interviewed and attempts were made to include all family members in the interviews. The interview was deliberately unstructured, allowing the respondent to develop his/her narrative.

The family narrative was collected, recorded, and analysed in the same manner as the individual child's narrative. After the individual interview each respondent was contacted to summarize the findings of the interview and to explore any areas which were not adequately addressed.

The data was analysed through narrative analysis and the study concluded that the foster care experience can be seen as a blow for foster parents' own children. All interviewed children felt they had lost something through the foster care experience: loss of family closeness, loss of parents' time and attention, loss of place in the family.

Discourse analysis

This concept is controversial and not entirely unambiguous. Definitions vary, both with respect to what the concept embraces and the importance of discourses. One definition of the term discourse is *"a particular way of describing and understanding the world (or some part of the world)"* [30].

Discourse analysis is a method of critically reading texts. The researcher seeks to understand how and why language is used as it is. Meanings and patterns are analysed. The function of discourse analysis is to identify and describe discourses. Characteristic for a discourse analysis is that it treats texts as data. The aim of discourse analysis is not to disclose what people really mean, or the way things really are, because the social constructionist foundation for discourse analysis means that this "reality" does not exist. The only reality is language and how this represents the world. Therefore language is a construction and all we can study is just how different expressions or discourses are constructed [11].

References

See main document, page 39.

Appendix 2. Quality assessment checklist for qualitative research studies – patients' and clients' perspectives

SBU's check-list for quality assessment is an adaptation based on previously published material [1,2].

Author:		_ Year:	Iden	Identification no:					
Overall assess	ment of study qua	lity:							
	High 🗖	Moderate 🗖	Low						
		nation is not retrievable f		er.					
• There are con		n the question is not rele on to some of the questic s document.							
			Yes	No	Unclear	N/A			
1. Aim									
	based on a well-defir well-formulated res	ned statement of the earch question?							
Comments on a	ims, discussion of pr	oblem, research questio	ns, etc						

	Yes	No	Unclear	
2. Sample selection				
a) Is the sample selection relevant?				
b) Is the method of selection clearly described?				
c) Is the context clearly described?				
d) Is a relevant ethical discussion included?				
e) Is the relationship between the researcher and the selected sample clearly described?				
Comments on sample selection, patient characteristics, context, etc	2			
3. Data collection				
a) Is the data collection procedure clearly described?				
b) Is the data collection relevant?				
c) Has data saturation been achieved?				
d) Has the researcher managed his own pre- understanding in relation to the data collection?				
Comments on data collection, data saturation etc				
4. Analysis				
a) Is the analysis clearly described?				
b) Is the method of analysis relevant in relation to the data collection procedure?				
c) Has saturation in terms of analysis been achieved?				
d) Has the researcher managed his own pre- understanding in relation to the analysis?				
Comments on method of analysis, saturation etc				
5. Results				
a) Are the results logical?				
b) Are the results comprehensible?				
c) Are the results clearly described?				
d) Are the results presented in relation to a theoretical framework?				
e) Is a hypothesis, theory or model generated?				
f) Are the results transferable to a similar setting (context)?				

Comments of clarification to the Quality assessment check-list for qualitative research studies – patients' and clients' perspectives:

1. Aim

The following aspects should be considered:

- the aim of the study
- why it is important
- its relevance
- whether qualitative research methods are appropriate for investigating the field/answering the research question.

2. Sample selection

The following aspects should be considered:

- whether the researcher has presented the background to the chosen method of sample selection
- whether the researcher has presented the procedure for selecting the participants
- whether the researcher has presented the reasons for selecting the participants
- whether the researcher has stated the number of participants selected
- whether the researcher has described whether anyone declined to participate and if so, why
- whether the researcher emphasises ethical aspects in more detail than merely "informed consent" and "ethical approval"
- whether the researcher has described the relationship between the researcher and the informant and how this might have influenced data collection, e.g. a debt of gratitude, dependent relationship etc.

3. Data collection

The following aspects should be considered:

- if the setting for data collection was justified
- if the method used to collect the data is described (e.g. in-depth interview, semi-structured interview, focus group, observations, etc)
- if the researcher has motivated the choice of data collection method
- if it is explicitly disclosed how the selected method of data collection was undertaken (e.g. who conducted the interview, how long the interview took, whether an interview guide was used, where the interview was conducted, how many observations were made, etc)
- if the method was modified during the study (if so, is it described how and why this was done)
- if the collected data are clear (e.g. video or audio recording, notes, etc)
- if the researcher has discussed whether saturation has been reached, i.e. when further data collection does not yield any new data (not always applicable)
- if an argument on saturation is applicable, consider whether it is reasonable, i.e. actually validated on good grounds.

4. Analysis

The following aspects should be considered:

- if the analytical process is described in detail
- if the analytical process is in accordance with any theoretical explanation or proposal on which the data collection was founded
- if the analysis is based on a theme, is it described how this theme was arrived at?
- if tables have been used to clarify the analytical process
- if the researcher has critically reviewed his own role, potential bias or influence on the analytical process
- if there is saturation of analysis (is it possible to find more themes based on the citations presented?).

5. Results

The following aspects should be considered:

- if the results/findings been discussed in relation to the aims of the study or the research question
- if adequate reasoning about the results is presented or if the results comprise merely citations/presentation of data
- if the results are presented clearly (e.g. is it easy to distinguish between citation/data and the researcher's own input)
- if the results are presented with reference to the theoretical explanation or proposal on which the data collection and analysis were based
- if adequate data have been presented to support the results to what extent contradictory data have been highlighted and presented
- if the researcher has critically reviewed his own role, potential bias or influence with respect to the analytical process
- if the researcher has discussed the transferability of the results or other areas of application for the results.

References

- 1. Bahtsevani C. In search of evidence-based practices: exploring factors influencing evidence-based practice and implementation of clinical practice guidelines. Malmö: Malmö högskola; 2008.
- 2. Willman A, Stoltz P, Bahtsevani C. Evidensbaserad omvårdnad. En bro mellan forskning och klinisk verksamhet. Studentlitteratur; 2006.