Work Package 4: Development of analytical framework to perform comprehensive evaluation using Multi-Criteria Decision Analysis

Focus group: Austria

WP leader:
Institute of Health Policy & Management, Erasmus University Rotterdam, the Netherlands

Authors
Susanna Ulinski, Astrid Segert, Thomas Czypionka
with the assistance of Bettina Gehrer

Date
September, 2016
Contents

1. General Information ................................................................................................................. 4

   Agenda .................................................................................................................................. 4

   Participants ............................................................................................................................... 4

   Recruitment procedure .......................................................................................................... 5

2. Content analysis ..................................................................................................................... 6

   Thoughts about what’s important in health and care (part one) ............................................. 6

   Top ten most important outcomes in health and care (part two) ......................................... 12

3. Conclusion and discussion ..................................................................................................... 17

4. Appendix ................................................................................................................................ 18

   Top-ten lists ............................................................................................................................. 18

   Photographs ............................................................................................................................ 21
1. General Information

Agenda

The focus group for work package four was held on September 2nd, 2016 at the Institute for Advanced Studies in Vienna. It was scheduled from 9.30 am to 11.30 am, but effectively lasted until noon. The agenda was as follows:

- Welcome (20 min)
- First discussion on what it means to be healthy (20 min)
- Second discussion on what’s important in care (20 min)
- Break (20 min)
- Ranking of results on cards (35 min)
- Windup (5 min)

The following researchers participated in the focus group:

- Dr. Astrid Segert (leader and moderator of the whole focus group)
- Susanna Ulinski, MSc MA (flip-charts and assistance)
- Bettina Gehrer, BSc (note-taking)

Moreover, the focus group discussion was recorded after obtaining the explicit approval of the participants.

Participants

The focus group consisted of 7 participants, 5 men and 2 women. The ages ranged from 62 to 84, with a mean age of 73. Variation in types of multi-morbidity existed, as can be seen in Table 1. None of the participants took part in a care programme evaluated by SELFIE. A group photo of the participants can be found in the appendix.
Table 1: Focus group participants

<table>
<thead>
<tr>
<th>Participant code</th>
<th>Gender</th>
<th>Age</th>
<th>Multi-morbidity</th>
<th>Recruitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>M</td>
<td>70</td>
<td>Diabetes, herniated disc</td>
<td>Via the patient ombudsmen</td>
</tr>
<tr>
<td>P2</td>
<td>F</td>
<td>66</td>
<td>Crohn’s disease, renal carcinoma (kidney cancer)</td>
<td>Via Abbvie (pharma company)</td>
</tr>
<tr>
<td>P3</td>
<td>M</td>
<td>62</td>
<td>Sleep apnea, trachyonychia</td>
<td>Via the patient ombudsmen</td>
</tr>
<tr>
<td>P4</td>
<td>F</td>
<td>72</td>
<td>Herniated disc, polyarthritis and lupus erythematoses</td>
<td>Via the patient ombudsmen</td>
</tr>
<tr>
<td>P5</td>
<td>M</td>
<td>82</td>
<td>Diabetes</td>
<td>Via Aktive Diabetiker Austria (self-help group)</td>
</tr>
<tr>
<td>P6</td>
<td>M</td>
<td>74</td>
<td>Portal vein thrombosis, herniated disc, arthrosis</td>
<td>Via the umbrella organisation of social organisations in Vienna</td>
</tr>
<tr>
<td>P7</td>
<td>M</td>
<td>84</td>
<td>Kidney cancer, bladder tumor, herniated disc</td>
<td>Via the patient ombudsmen</td>
</tr>
</tbody>
</table>

Recruitment procedure

The recruitment procedure for participants started with the national stakeholder workshop on June 8th, 2016. We approached all present stakeholders and kindly asked them for their help. The patient ombudsman for Lower Austria was able to establish contacts with four patients through a personal friendship with a doctor. Two care providers from the workshop helped to establish two patient contacts. In addition to that, we contacted self-help groups (one patient) and a personal contact from a pharma company referred two patients. We also created a flyer and hung it up in GP practices in Vienna, but no single patient responded to it (cf. Figure 10). A compensation of 40 EUR was offered for the participation in the focus group. Recruitment was ended on Friday, August 12. A total of nine patients was preselected by our supporting organisations and further called and/or e-mailed by us. The patients were also called again one day before the focus group to remind them of their participation. Seven patients participated in the focus group, one patient had no time at the chosen date and one patient was not able to reach.
2. Content analysis

After the welcome and short individual introductions, we presented the questions for discussion. They were also written on the board for the patients to keep focus. The patients were very active and reflective in the process, but also supportive of each other in voicing their opinions and concerns. Due to the time the patients took to discuss the specific thoughts on outcomes in step one, not much time was left for step two, the generalization of outcomes. Thus, the outcomes were generalised during the flip-chart writing process and during the break when the new concepts were added on new cards. Photos of the original flipcharts can be found in the appendix.

Thoughts about what’s important in health and care (part one)

Due to the active participation of patients, we filled eight flip-charts with aspects that are important in health, well-being and care for the participants. The majority of concepts was found on the already existing cards. During the first question, it was difficult for the patients to remain within the question of health, as they frequently mentioned their GPs and the care process. This indicates that individual health and well-being is closely linked to the care process. Some patients emphasised that their individual well-being depends on the ability to participate in employment and society, and this in turn depends on how the care is adapted to their daily needs. It is for example not possible for them to use insulin if they are in a meeting. In the discussion, the patients also mentioned the acceptance by others and the social support of partners, families and self-help groups. Patients have a right to be listened to and to be angry if they have a bad day. Similarly, they have to accept the bad days in order to happily enjoy the good days. They have also adjusted their physical activities to their illnesses, but it is important for them to remain physically active within their possibilities. New cards that were made for patients to include in the ranking describe getting something off one’s chest, not to be reduced to the disease, surrounding area takes care of someone’s needs and treatments are compatible with work. Table 2 includes the most important patients’ statements on what it means to be healthy.

Table 2: Most important statements on what it means to be healthy

| P1: For me it means to be 30 years old because I was healthy at that time. |
| P2: For me it is wellbeing, just wellbeing in any form. |
| P6: I have to say, for me it’s important to be agile and open-minded. |
| P4: I want to enjoy my life, even though I’ve these diseases. That means, just being full of life. |
| P3: I agree with that, the quality of life should not be limited. |
P2: The meaningfulness of my existence... I wish that people treat me in a respectful manner, because it’s true, I am sick, but the disease is not me. I don’t want to be reduced to my diseases.
P2: Being respected...in particular from someone’s environment. There’s no hindsight...I’m always saying “I’m not lacking brain, I’m sick” because people sometimes treat me very derogatory. It is important that our environment regards us as full members of society. They should not reduce us to our incurred expenses, because I will not feel miserable, I want to be a part of society. And I’ve heard it very often how “expensive we are” [for the health system].
P4: Partnership must fit well.
P3: There must be comprehension and appreciation [in the partnership]
P5: That there is no reason for people to hide themselves from their environment. That means for example, sometimes I observe people going on the toilet for injecting their insulin.
P2: That’s true. People have to talk to each other, because when they are talking, people can get enlightened by information, and then they probably become more understanding.
P1: If I am at home, I don’t leave the room to get my injection of insulin, but if I’m in public, I also go and get it [the injection] on toilet.
P1: I’m not feeling healthy any more, and I think it is for the most part the blame of the herniated disc. At age 30 and until half a year I was full of energy and creative, but since I got this slipped disc, everything is gone, everything...Now I don’t have any power, walking is getting really hard for me and I suffer from loss of appetite. The only thing which makes me happy is to go into the beer garden, smoke a cigar and drink some coffee. And if I die then it would be OK. This doesn’t mean that I’m not afraid of death but I would accept it.
[Question about what’s the difference between feeling healthy and feeling good]
P7: I have this chronic disease but still I’m feeling good. But it is important to have discipline and obey doctor’s advice. So I’m feeling good and healthy if I follow the plan – no smoking, no alcohol, being sportive, eating healthy...
P6: Although I’m 65, I want to have a few more years to live. Well-being means to me to have good and bad days. The most important thing is to make the most of good days and enjoy them. (...) And as I mentioned before, there are good and bad days, on bad days I cannot even drive with the car. Then doctors often say to me that I need a surgery or some special medication, but I go every second week to a masseur and to a doctor in osteopathy and they can help me to overcome bad days without taking many different tablets.
P2: It is important to accept the disease and to accept that there are bad days. I always say that you need a healthy portion of fatalism; you cannot defense yourself against the inevitable. And for me personally, it is important to be allowed to say that I’m feeling bad. I’m tired of being the brave
patient, when in truth I’m mortally ill. And I have the right to say how I’m really feeling, as long as I don’t hurt anybody. For example, I cannot go to the park yelling at strangers just because I’m feeling bad, but I have the right that people are hearing and respecting me.

Why are people going to psychiatrist? - Because they need someone listening to them. That’s the reason why partnership is a very important point mentioned already before.

Also being active is necessary for wellbeing. I was always very athletic nowadays only limited but it works if you adapt your activities to your physical ability.

P7: That’s true, though I cannot climb mountains anymore but I can walk through different parks and I can still use the stairways.

P4: Life was not always easy for me and therefore I have suffered different physical damages. Now I’m married for 33 years to my husband and since I was 16 he has always supported me. I can always rely on him.

P3: I agree with that. I owe my partner the support and assist him or her 100 percent.

P4: My husband was a carpenter, but because of his illness he was severely limited in his activities, which was an enormous emotional burden to him.

P3: Therefore talking with someone is so important, because you can get your problems of your chest and then it bothered me no longer.

- Everybody agreed

P7: I have been a widower for ten years now and my contact person is my daughter or my granddaughter. So not only the partnership but the whole family is important in case of such diseases.

P6: I have to add that I’ve been married for 45 years, have three grandchildren and these are my contact persons, but also my son, who lives in America or one of my two daughters. One of them is even a doctor. In general I think that talking can have a healing effect.

- Everybody agreed

P2: That is exactly what self-help groups are for. In such a group, I don’t need to explain everything because everybody knows of what I’m talking about, there’s understanding within the group.

P5: To adapt any treatments to life. For example, there was this nurse saying to me, at the beginning of my diabetes treatment, that I have to eat an orange exactly at 11. But at 11, she was in surgery, so she didn’t have time to bring me that orange.

P5: There was a woman, who took off her jeans in public to inject herself insulin. But she told me that her son won’t do this. He’s not going to take off his trousers in front of his classmates at school. That’s a problem, because he needs the insulin. The doctor’s not giving him the advice to inject the insulin through his trousers because he’s not allowed to. But that is important, because we must
adapt the necessity of treatments to our lives in an undisturbing manner. For me personally it was very disturbing some years ago. For years I had an insulin therapy where I had to eat after two hours, but I couldn’t. There were many people watching me and it was impossible for me to eat. These moments are really unpleasant experiences. Therefore it is important that doctors know how to adapt treatments and therapies to life, but there are lots of doctors who cannot do this.

P2: But this isn’t possible, because doctors gave me the advice to live as normally as possible, but if I have to go to the ambulance or to doctors twice a month for half a day minimum, this is not possible. There are long waiting times because the system is lousy organized. But countryside, I’ve seen doctor’s offices where you don’t have to wait long for the doctor. So it is possible with the right organization.

The aspects developed by the participants are listed in Table 3. The left column shows aspects mentioned by the patients and the right column whether we assigned the aspect to an existing concept on the prepared cards or created an own card for it. Photos of the original flipcharts can be found in the appendix.

Table 3: Thoughts about what’s important in health/well-being

<table>
<thead>
<tr>
<th>Flip-Chart</th>
<th>Outcomes on cards (existing, new*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of 30 and wellbeing</td>
<td>Energy and fatigue</td>
</tr>
<tr>
<td>Being agile and open-minded</td>
<td>Maintaining independence</td>
</tr>
<tr>
<td>Treatments adapted to life and work</td>
<td>Treatments are compatible with work*</td>
</tr>
<tr>
<td>Keep moving</td>
<td>Lifestyle / energy and fatigue / physical mobility</td>
</tr>
<tr>
<td>Obey treatment plans (take in medication, have no overweight)</td>
<td>Compliance/adherence to treatment</td>
</tr>
<tr>
<td>Enjoyment of life despite disease</td>
<td>Enjoyment of life</td>
</tr>
<tr>
<td>Allowing help from the partner/partnership</td>
<td>Social support</td>
</tr>
<tr>
<td>Exercise a profession/Staying busy</td>
<td>Maintaining independence</td>
</tr>
<tr>
<td>Finding contact persons (relatives, self-help groups, partners,...)</td>
<td>Social support</td>
</tr>
<tr>
<td>Not having to hide from somebody (e.g. inject insulin on toilet)</td>
<td>Surrounding area takes care of someone’s needs*</td>
</tr>
<tr>
<td>Being a full member of society</td>
<td>Maintaining social status</td>
</tr>
<tr>
<td>Being respected by others</td>
<td>Respect from others</td>
</tr>
<tr>
<td>Right to be listened to</td>
<td>Get something off one’s chest*</td>
</tr>
<tr>
<td>Not to be reduced to incurred costs</td>
<td>Maintaining dignity / Respect from others</td>
</tr>
<tr>
<td>Not to be reduced to the disease</td>
<td>Not to be reduced to the disease*</td>
</tr>
<tr>
<td>Making the most of good days</td>
<td>Enjoyment of life</td>
</tr>
</tbody>
</table>
Not having to take a lot of pills | Living comfortably / Avoid unnecessary treatments*
---|---
Acceptance of the disease | Coping
Energy and creativity | Energy and fatigue
Physical mobility and appetite | Physical mobility
Beer garden and cigarettes | Enjoyment of life
Feeling comfortable vs. healthy | Living comfortably

The second question addressed what patients perceive to be good care. Patients value if their doctors take time to holistically assess their needs. As GPs are often under time pressure, they might immediately visit their specialists, who have more time for them. Moreover, patients demand to be respected by doctors as a person, but also as a shared decision maker. Training offers how to deal with e.g. diabetes are hardly available in Austria and much needed by the patients. Following on from this, the patients criticised the distribution of competencies within the healthcare systems. Nurses should be allowed to offer trainings, as they are better suited than doctors to do so. In other countries diabetes nurses are state of the art, and we should learn from country examples. Respect is a recurring topic also on the health system level, when the patients feel that they have contributed for a long time into a solidary system, and now, when they need it, they are perceived as a burden and many costs are not covered.

Also for care many concepts that were discussed were already written on the existing cards. Nevertheless, more novel concepts were brought up than for health and well-being. These novel concepts include doctors taking time for their patients, the integration of self-help groups, a new distribution of competencies within the health system, avoiding unnecessary treatments, a solidary distribution of funds, good training offers, and learning from different country experiences. Two patients were active members of self-help groups and they criticised that they could offer support for patients, but are excluded from the care process.

Table 4: Most important statements on what good care is

P7: I have very good specialists. They make accurate diagnosis; they take time for the patients. If a treatment lasts longer, it’s okay. At the family doctor you have to hurry because he only has ten minutes and then it’s the next patient’s turn. So I visit the family doctor only for minor problems, otherwise I visit a specialist.

P1: A good doctor has time for his patients and is an excellent diagnostician and psychiatrist.

P2: A good doctor is someone who greets me friendly and who treats me without condescension. He grants me a say in things concerning my treatments and medication, because we decide together.
And teamwork is also important, between the patient, the doctor and the medical staff. I take his competence for granted, but even if he’s competent but unfriendly I’d never visit such a doctor.

P5: The problem is that family doctors often are overloaded; they don’t have time to offer trainings...

P6: Important is a shared-decision making, and not the doctor’s telling me “You have to do this; you have to do that...” Because I want to know what’s good for me to do and what is not.

For example osteopathy is not accepted in Austria; in Switzerland it is established. But the latest methods must be identified as soon as possible in order to benefit from them.

P5: (...) In Austria we need more training so that also nurses can treat somebody with diabetes.

P6: Private therapies are very expensive...Thank god, I can afford it.

P1: I was once at a private doctor who only was expensive, but didn’t do anything, and then I went to my family doctor who treated me the right way, gave me the right medication and helped me.

P2: In other countries, like Scandinavia, there is a better health care and education. For example self-help groups are better included in the system. Important is social policy. In Austria, there are enough good ideas but they are not possible to realize because of our policy. So being well cared for means to me that the system is learning fast from good examples of other countries, and adapt these good points.

P6: Two years ago I had a magnetic resonance treatment – waiting period about 8 – 10 weeks. Then I’ve paid it myself and the waiting period shortened to 2 days. Then I’ve applied for a stay at a health spa and was rejected twice, so what did I do, I privately went there. But these costs aren’t necessary, because I’ve paid into the system for about 50 years and now I cannot get these services. There is a solidarity principle, but nowadays it is obsolete and not fair anymore.

P2: We are just old and uninteresting, and they leave us alone in the system.

P5: Financing from a single source is absent in Austria and therefore we [older people] are very expensive for the system. The system is not working well because it’s obsolete.

P2: The education and training in nursing has to change and I think it is on the path for change. In Austria there’s an important thing missing – professionals need to cooperate in interdisciplinary teams.

P3: I am happy with the system, I have a good doctor, and I live disciplined.

P6: The best doctor is useless if someone lives without any discipline.

P5: I think that each diabetic has to know what it means to him to be a diabetic and what is going on inside his body because of this disease. The disease is constantly changing, because of a person’s age or...The affected person has to know about different therapies, the doctor can offer assistance but the responsibility is with the patients. With diabetes you cannot do the same therapy for 20 years and longer, because you have to change your treatments every few years, but then there’s the need
for trainings. Who pays for these trainings?

The aspects identified by the patients on what is important in their care are shown in Table 5. The left column shows aspects mentioned by the patients and the right column whether we assigned the aspect to an existing concept on the prepared cards or created an own card for it.

Table 5: Thoughts about what’s important in care

<table>
<thead>
<tr>
<th>Flip-Chart</th>
<th>Outcomes on cards (existing, new*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors take time for their patients</td>
<td>Doctors take time for their patients*</td>
</tr>
<tr>
<td>Professionals take notice of their patients</td>
<td>Holistic assessment</td>
</tr>
<tr>
<td>Integrate self-help group in social policy</td>
<td>Integration of self-help groups*</td>
</tr>
<tr>
<td>Learn from other countries</td>
<td>Learning from different country experiences*</td>
</tr>
<tr>
<td>Waiting periods and treatments</td>
<td>Timely access, individualized care planning, tailored care</td>
</tr>
<tr>
<td>Obsolete solidarity principle</td>
<td>Solidary distribution of funds*</td>
</tr>
<tr>
<td>No work in interdisciplinary teams</td>
<td>Team work and collaboration between professionals / new distribution of competencies within the health system*</td>
</tr>
<tr>
<td>Competent care</td>
<td>Pro-active, preventive-oriented care / individualized care planning / tailored care</td>
</tr>
<tr>
<td>Avoid unnecessary treatments</td>
<td>Avoid unnecessary treatments*</td>
</tr>
<tr>
<td>Latest methods must be realized</td>
<td>Confidence in knowledge and skills in professionals</td>
</tr>
<tr>
<td>Own treatment discipline</td>
<td>Compliance/adherence to treatment</td>
</tr>
<tr>
<td>Shared-decision making and teamwork</td>
<td>Shared decision-making / team work and collaboration between professionals</td>
</tr>
<tr>
<td>Personal responsibility of patients – necessity of trainings</td>
<td>Good training offers*</td>
</tr>
</tbody>
</table>

**Top ten most important outcomes in health and care (part two)**

At the start of part two, each of the patients received an own set of cards. This should facilitate the ranking process. The cards included the 38 concepts of health and well-being (34 pre-decided and four new), 24 concepts on care (17 pre-decided and seven new) and four concepts of costs (all pre-decided). The patients then chose the ten most important cards for them and placed them individually on the table in front of them. In the next step, they were asked to rank the cards. However, the patients voiced their discomfort with having to rank outcomes of health and of care together. They pointed out that it is not possible to weigh factors of their own condition, e.g.,
physical mobility, against factors of care, e.g., team work and collaboration between professionals. When the moderator politely asked them to do so anyway, they followed the instructions. One participant chose nine cards and two participants chose 11 cards. Four participants chose 10 cards. The individual rankings can be found in the appendix.

Table 6 shows the concepts that made it on the top-ten lists and their frequency. On the patient’s top-ten lists the most concepts came from health and well-being (24) followed by care (14) and only two concepts from costs were included. In total, 40 different concepts were listed. When discussing the most important factors of health and well-being, the most mentioned concepts were cognitive functioning (4), energy and fatigue (4), pain and discomfort (3) and maintaining social relationships (3). The most important characteristics of good care include doctors who take time for their patients (4), the integration of self-help groups (3), and a new distribution of competencies within the health system (3).

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health &amp; Well-being (23)</strong></td>
<td></td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>4</td>
</tr>
<tr>
<td>Energy and fatigue</td>
<td>4</td>
</tr>
<tr>
<td>Pain and discomfort</td>
<td>3</td>
</tr>
<tr>
<td>Social relationships</td>
<td>3</td>
</tr>
<tr>
<td><strong>Get something off one's chest</strong>*</td>
<td>2</td>
</tr>
<tr>
<td>Enjoyment of life</td>
<td>2</td>
</tr>
<tr>
<td>Biomedical outcomes</td>
<td>2</td>
</tr>
<tr>
<td>Positive frame of mind, resilience</td>
<td>2</td>
</tr>
<tr>
<td>Maintaining independence</td>
<td>2</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>2</td>
</tr>
<tr>
<td>Maintaining social status</td>
<td>2</td>
</tr>
<tr>
<td>Listless</td>
<td>1</td>
</tr>
<tr>
<td>Loneliness</td>
<td>1</td>
</tr>
<tr>
<td><strong>Not being reduced to the disease</strong>*</td>
<td>1</td>
</tr>
<tr>
<td><strong>Surrounding area takes care of someone's needs</strong>*</td>
<td>1</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>1</td>
</tr>
<tr>
<td>Coping</td>
<td>1</td>
</tr>
<tr>
<td>Living comfortably</td>
<td>1</td>
</tr>
<tr>
<td>Social support</td>
<td>1</td>
</tr>
<tr>
<td>Societal participation</td>
<td>1</td>
</tr>
</tbody>
</table>
In the next step, patients were asked to jointly agree on a list of the 10 most important aspects in health and care. One after the other, the patients were invited to read out the cards they would like to include. The moderator then asked the other patients whether they have a similar card in their ranking or whether they object. As the patients were very considerate and never objected to a concept, the moderator based the decision whether to include the concept on the support it received, often in the form of nodding or raising their same card. At the end of the session, patients have prioritized 14 concepts. Unfortunately, as we were already over time, there was no time left to reduce the 14 concepts to 10. These 14 most important concepts include:

| Maintaining dignity                  | 1 |
| Treatments are compatible with work* | 1 |
| Compliance/adherence to treatments   | 1 |
| Care (15)                             |   |
| Doctors take time for their patients*| 4 |
| Integration of self-help groups*     | 3 |
| New distribution of competencies within the health system* | 3 |
| Shared-decision making               | 2 |
| Shared information between professionals and providers | 2 |
| Avoid unnecessary treatments*        | 2 |
| Respectful interaction between provider-patient | 2 |
| Solidary distribution of funds*      | 2 |
| Good training offers*                | 1 |
| Learning from different country experience* | 1 |
| Good communication                   | 1 |
| Holistic assessment                  | 1 |
| Confidence in knowledge and skills in professionals | 1 |
| Satisfaction with care process       | 1 |
| Individualised care planning         | 1 |
| Costs (2)                            |   |
| Service and support coverage         | 2 |
| Loss of income - patient             | 1 |
Health and wellbeing

- Pain and discomfort
- Lifestyle
- Cognitive functioning
- Energy and fatigue
- Maintaining independence
- Maintaining social status
- Social support
- **Treatments are compatible with work***

Care

- Respectful interaction between provider-patient
- Shared information between professional and providers
- **Training offers***
- **New distribution of competencies within the health system***
- **Integration of self-help groups***

Costs

- Service and support coverage

Table 7 shows statements made during the process of prioritization. It was not a discussion, but more patients talking one after the other with the moderator.

*Table 7: Statements on prioritizing what’s important in “health/well-being” and “care”*

<p>| P5: As a result of its disease, a patient is too tired for initiative for its own. |
| P4: Freedom from pain |
| P1: New distribution of competencies within the health system and financing from one single source |
| P2: Not to be reduced to the disease and shared-decision making (+ social policy) |
| P3: Respectful treatment of others |
| P6: Education and trainings, information |
| P7: Healthy lifestyle |
| P6: Cognitive functioning...need it to achieve something in life (School, apprenticeship ...) but not only when you’re young, also if you’re old, your cognitive functioning is really important. |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>P4:</td>
<td>I agree with that. It’s important for your whole life, because it guarantees you that you can be a part of society; that you can participate in life.</td>
</tr>
<tr>
<td>P4:</td>
<td>A positive frame of mind</td>
</tr>
<tr>
<td>P5:</td>
<td>Energy and fatigue</td>
</tr>
<tr>
<td>P2:</td>
<td>No paternalism – People always ask me “Are you allowed to do this?” and what should I say...I’m allowed to do everything</td>
</tr>
<tr>
<td>P7:</td>
<td>Own way of life</td>
</tr>
<tr>
<td>P4:</td>
<td>Having good relationships to other persons</td>
</tr>
<tr>
<td>P5:</td>
<td>Retain social status (dignity) and that treatments are compatible with work</td>
</tr>
<tr>
<td>P5:</td>
<td>Social support trough social networks</td>
</tr>
<tr>
<td>P6:</td>
<td>Avoid unnecessary treatments + self-help groups</td>
</tr>
<tr>
<td>P5:</td>
<td>Coping with additional payments</td>
</tr>
<tr>
<td>P5:</td>
<td>Oh we’ve forgotten an important theme. What about the internet? Everybody has to know how it works in time of Dr. Google.</td>
</tr>
<tr>
<td>P2:</td>
<td>The internet is very important but you have to be careful, because it can also be dangerous.</td>
</tr>
</tbody>
</table>
3. Conclusion and discussion

In conclusion, the recruited patients were very active and enthusiastic participants and enjoyed the exchange of ideas. Moreover, they highly appreciated that their views were taken into account by this research project.

The participants easily understood the tasks and showed a great level of knowledge about the Austrian and even international health care systems. They are certainly more informed and concerned about their health and care than the average multimorbid patient. Similarly, they were very reflective about their illnesses and their needs as both a patient and a person. This confirms a likely recruitment bias. The patients were preselected by our partners, probably due to their mental capacity and openness.

The participants showed great respect for each other and acknowledged the difficulties of coping with the various illnesses. They were very supportive of all statements and never criticised another group member. One researcher had the impression that it helped the patients to talk about their care and to be taken seriously, similar to discussing in a self-help group. Likewise, the participants often mentioned that it is very important for them to be listened to by society and that talking is an important form of therapy. Due this active engagement of the participants, the time frame for the focus group was too tight. At the end, many patients thanked the researchers for the opportunity to participate.
4. Appendix

Top-ten lists

Participant 1:

1. Pain and discomfort
2. Listless
3. Loneliness
4. Social relationships
5. Energy and fatigue
6. Good communication
7. Shared information between professionals and providers
8. Get something off one’s chest*
9. Doctors take time for their patients*
10. Avoid unnecessary treatments*

Participant 2:

1. Not being reduced to the disease*
2. Integration of self-help groups*
3. Shared-decision making
4. Holistic assessment
5. Respectful interaction between provider-patient
6. Surrounding area takes care of someone’s needs*
7. New distribution of competencies within the health system*
8. Solidary distribution of funds*
9. Self-esteem
10. Coping

Participant 3:

1. Cognitive functioning
2. Energy and fatigue
3. Living comfortably
4. Enjoyment of life
5. Solidary distribution of funds*
6. Biomedical outcomes
7. **Doctors take time for their patients***
8. **Get something off one’s chest***
9. Respectful interaction between provider-patient
10. Social relationships

**Participant 4:**

1. Shared-decision making
2. Loss of income - patient
3. Service and support coverage
4. Confidence in knowledge and skills in professionals
5. Pain and discomfort
6. Positive frame of mind, resilience
7. Energy and fatigue
8. Cognitive functioning
9. Enjoyment of life
10. -

**Participant 5:**

1. **New distribution of competencies within the health system***
2. **Treatments are compatible with work***
3. **Good training offers***
4. Maintaining social status
5. Lifestyle
6. Maintaining independence
7. Social support
8. Societal participation
9. **Integration of self-help groups***
10. **Learning from different country experience***
11. Service and support coverage

**Participant 6:**

1. **Avoid unnecessary treatments***
2. Cognitive functioning
3. Energy and fatigue
4. Pain and discomfort
5. Maintaining social status
6. **Doctors take time for their patients***
7. **New distribution of competencies within the health system***
8. Shared information between professionals and providers
9. **Integration of self-help groups***
10. Social relationships

**Participant 7:**

1. Compliance/adherence to treatments
2. Biomedical outcomes
3. Individualised care planning
4. Satisfaction with care process
5. **Doctors take time for their patients***
6. Cognitive functioning
7. Maintaining dignity
8. Lifestyle
9. Maintaining independence
10. Physical mobility
11. Positive frame of mind, resilience
Photographs

Figure 1: Flip-chart 1

- Alter von 30
- Wohlbefinden
- Auch + Aufgeschlossen
- Therapien an Leben angepasst/einbauen in Rhythmus
- Bewegung
- Behandlungsdisciplin: Medikamente
- unb.
- Übergewicht
- Leben trotz Krankheit
- genießen
Respekt - nicht als Patient bezeichnet
Ärzte nehmen einen Wahr
Umwelt - keine Rückkehr aus Bedürfnisse, 2) Nicht auf Kosten reduziert
Vollwertiges Gesellschaftsm
Verständnis Partnerschaft
Nicht verstecken (Insulin am Kloßprizich)
Termine

* Therapie vereinbar mit Erwerbsarbeit.
* Patient verantwortlich für Therapie, Doktor Hilfstelle
  → Patient braucht Schulung.

* Energie + Kreativität
* Mobilität + Appetit
* Schöningarten + Zigarette
* Wohlfühlen vs. Gesund fühlen
Figure 4: Flip-chart 4

Wohlfühlen, wenn man Therapie einhält
Gute Tage ausnützen
Arzt nimmt sich Zeit
Junge Ärzte mit Biss vs. alte Ärzte
Nicht viel Pulver nehmen
Krankheit akzeptieren
Schlechte Tage akzeptieren
Recht, dass jemand zuhört
Hilfe von Partner, wenn man sich selbst nicht versorgen kann
• Beruf ausüben
• von Seele sprechen
• Kinder + Enkel Ansprechpartner
Selbsthilfegruppe - Gespräch
Guter Arzt:

- Nimmt sich Zeit
- Fachlich gut: guter Psychologe + Diagnostiker
- größt hörlich, aus Augenhöhe schnell Termine gemeinsam Therapie besprechen, Teamarbeit
- Hausärzte mit Diabetestherapie fördert
- Osteopathie, neueste Methoden müssen anerkannt werden
Selbsthilfe in Sozialpolitik einbinden

- Aus anderen Ländern lernen
- Wartezeit f. Behandlung
- Kur - abgelehnt, privat bezahlt
- Solidaritätsprinzip nicht mehr gerecht
  → Alt + uninteressant
  → "Sollen sterben"

Keine interdisziplinäre Arbeit

Eigene Behandlungsdisziplin

→ Erfahrung + Schulung von Diabetesberatern
Kosten

richtige fachliche Betreuung spart Kosten
Dänemark, Finnland Krankenschwestern machen Schulung, kann Arzt gar nicht

Hohe private Kosten, ohne Ego
Keine unnötigen Infusionen

"Vorwurf" Kosten zu vervoren
Mehr Kosten durch Behandlungsverzögerung (Hausarzt nicht insuliert, Krankenschwester darf nicht selbständig Arz
Figure 9: Most important outcomes in health and care
INTERNATIONALES FORSCHUNGSPROJEKT:
Versorgung von
chronisch mehrfach erkrankten PatientInnen in Österreich

Wir suchen Sie zur Teilnahme an einer Fokusgruppe!
Helfen Sie mit, die Pflege von chronisch mehrfach Erkrankten zu verbessern!

Das Institut für Höhere Studien untersucht im Rahmen des internationalen Forschungsprojektes SELFIE die Versorgung von multimorbid chronisch kranken Personen in Österreich. Für eine Fokusgruppe suchen wir deshalb Männer und Frauen ab 18 Jahren, die an mehreren chronischen Erkrankungen leiden.

In dieser Fokusgruppe bestehend aus max. 6 PatientInnen haben Sie die Gelegenheit, Ihre Erfahrungen mit dem österreichischen Gesundheits- und Pflegesystem mit uns zu teilen. Die Ergebnisse der Fokusgruppe werden anonym in das Forschungsprojekt einge-arbeitet.

Zeitrahm en:
Ein Vormittagstermin unter der Woche (ca. 2 Stunden) im Juli 2016

Aufwandsentschädigung: 40,- Euro

Studienleitung: Dr. Thomas Czypionka, IHS, Forschungsgruppenleiter, HealthEcon
Ansprechpartner: Dr. Markus Kraus, Tel: 01/59991-141; Email: kraus@ihs.ac.at

Für nähere Informationen stehen wir Ihnen gern zur Verfügung und freuen uns auf Ihren Anruf!
Figure 11: Photo with participants