What are needs?
- Assess patients in routine cancer care

Palliative Interventions
- Opening the black box of spez. PC RCTs
- Single interventions - Communication

Support coping
- Illness understanding
- Prognosis talk

Address symptoms
- Basic principles

Coordinate (professional) care
- Work as team - foresee

Prepare for End-of-life
- Work as team – foresee complications
What are your needs?
Unmet care needs in people living with advanced cancer: a systematic review

Cancer AND advanced disease AND needs (exp needs assessment, unmet need$, need$ assess$, perceived need$, support$ care need$, psycho$ need$, physical need$, exp symptom assessment, information need$)

23 included studies: 5 UK, 5 USA, 4 Australia, 3 Canada, 2 Netherlands, 1 each Hong Kong, Japan, Italy, and Denmark. 19 quantitative surveys (most used: Supportive Care Needs Survey in 6 studies), 4 qualitative studies (semistructured interviewing: individual or focus group).

→ 1/3 - 2/5 Patients have unmet needs

### Unmet care needs in people living with advanced cancer: a systematic review

#### Table 3  Most endorsed items of need (by domain) across studies using the Supportive Care Needs Survey

<table>
<thead>
<tr>
<th>Study</th>
<th>Psychological</th>
<th>Physical</th>
<th>ADL</th>
<th>Health system and informational</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Fears about the cancer spreading</td>
<td>Lack of energy/tiredness</td>
<td>Not being able to do the things you used to do</td>
<td>Having one member of staff with whom you can talk about your concerns</td>
<td>Sexuality: changes in sexual feelings/relationships (15 %)</td>
</tr>
<tr>
<td>Uchida  [37]</td>
<td>(79 %)</td>
<td>(48 %)</td>
<td>(46 %)</td>
<td>(67 %)</td>
<td>[37]</td>
</tr>
<tr>
<td>Waller  [8]</td>
<td>Concerns about the worries of those close to you (28 %)</td>
<td>Lack of energy/tiredness (26 %)</td>
<td>Not being able to do the things you used to do (33 %)</td>
<td>Information about managing illness and side effects (16 %)</td>
<td>Spiritual: uncertainty about the future (13 %)</td>
</tr>
<tr>
<td>Fitch   [26]</td>
<td>Fears about pain (28 %)</td>
<td>Pain (45 %)</td>
<td>Not being able to do the things you used to do (29 %)</td>
<td>Information about things you can do to help yourself get well (20 %)</td>
<td>[26]</td>
</tr>
<tr>
<td>Beesley [22]</td>
<td>Fears about the cancer spreading (25 %)</td>
<td>Lack of energy/tiredness (18 %)</td>
<td>Not being able to do the things you used to do (25 %)</td>
<td>Information about things you can do to help yourself get well (41 %)</td>
<td>[22]</td>
</tr>
<tr>
<td>Aranda  [20]</td>
<td>Concerns about the worries of those close to you (41 %)</td>
<td>Pain (28 %)</td>
<td></td>
<td>Having one member of staff with whom you can talk about your concerns (64 %)</td>
<td>[20]</td>
</tr>
<tr>
<td>Au      [21]</td>
<td>Worry that the results of treatment are beyond your control (18 %)</td>
<td>Lack of energy/tiredness (11 %)</td>
<td></td>
<td></td>
<td>[21]</td>
</tr>
</tbody>
</table>

Need versus Symptom versus Syndromes versus PRO

● **Symptom**: subjective experience, only patient can judge it
  - Intensity: visual-analogue (---), categorial (numbers), visual-categorial (Smiley) *EdmSymAssSca*
  - Impact: Work, QoL, Relationships, Mood, Physical Acivity
  - Distress

● **Syndrome**: «objective» Mechanisms for Symptoms
  - Bsp. Painsyndrome, Fatiguesyndrome

● **Patient Reported Outcome** (PRO)
  - Term often used «only» for Symptom
  - but all what is coming «from Patient»: e.g. physical Function

→ What tell these Data me (Clinician), if Patient requires a (medical) Intervention? Estimation of Priority, of Distress related to need, and of available Interventions

● **Need**: ability to profit from medical Intervention
  - May be dependent of available «Menu» (e.g.: experience new Spice)
  - expressed need, felt need, comparative need, normative need (Bradshaw)

*EORTC-QLQ-C30*  *Brief Fatigue Inventory*  *Distress Thermometer*  *Edmont Classific System-Cancer Pain*  *Single Item Fatigue*  *KPS*
Types / Taxonomy of needs

- **Directly from the patient after a request (felt need)**
- **Inferred from patient-reported events, triggers or contexts (comparative or normative need)**
- **Spontaneously expressed need of any kind**


That means for daily oncology practice:

- Ask patients (and family members) about their needs
- Be aware of standards your patient may profit from
- Assess patients with concrete tools for symptoms and for other needs (e.g. distress thermometer, newer tools)

Then deliver an (palliative) intervention
Current evidence of (specialized) Palliative Care
Systematic literature review: 49 RCTs, 19 only cancer pts


Cochrane review: early palliative care may have more beneficial effects on quality of life and symptom intensity than usual care

Metaanalysis
Statistically and clinically significant improvement of patient QoL and symptom burden at 1-3 mts
No consistent association of PC with survival

Narrative synthesis
PC consistently associated with improvement of advanced care planning, patient and caregiver satisfaction, lower health care utilization

Gärtner J et al. SLR & Meta-analysis BMJ 2017;357:j2925

“Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.”

<table>
<thead>
<tr>
<th>Type</th>
<th>Evidence Quality</th>
<th>Recommendation level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with advanced cancer</td>
<td><strong>Evidenced-based</strong></td>
<td>intermediate</td>
</tr>
<tr>
<td>- shall <strong>be referred</strong> to interdisciplinary palliative care teams</td>
<td></td>
<td>intermediate</td>
</tr>
<tr>
<td>- consultation available <strong>both inpatient and outpatient care</strong></td>
<td></td>
<td>intermediate</td>
</tr>
<tr>
<td>- <strong>early</strong> in the course of disease, <strong>alongside active</strong> treatment</td>
<td></td>
<td>intermediate</td>
</tr>
<tr>
<td>Newly diagnosed pts, referral &lt; 8 weeks</td>
<td><strong>In-formal consensus</strong></td>
<td>intermediate</td>
</tr>
<tr>
<td>Cancer patients with high symptom burden</td>
<td><strong>Evidence-based</strong></td>
<td>intermediate</td>
</tr>
<tr>
<td>and/or <strong>unmet</strong> physical or psychosocial needs outpatient cancer care programs shall use dedicated resources</td>
<td></td>
<td>intermediate</td>
</tr>
</tbody>
</table>

**For family caregivers in outpatient setting** | **Evidence-based** | low | weak |
Incurable Lung Cancer (NSCLC, SCLC, Mesoth)

Incurable non-CRC GI Cancer (pancreatic, esophageal, gastric, hepatobiliary)

Temel J et al. JCO 2016; Dec 28
Effects of specialized Palliative Care «Dose» of specialized PC in 24 weeks: 6.54 (mean, range 0-14)

Ferrrel BL et al. JCO 2017;35:96-112
Effects of specialized Palliative Care are different in incurable 350 Lung and non-CRC GI Cancer Patients (of eligible pts 20% refused, 24% not enrolled)

→ Once a month: recommended dose*

Temel J et al. JCO 2016; Dec 28
Ferrrel BL et al. JCO 2017;35:96-112
Essential components of palliative care may include:

- Rapport and relationship building with patients and family caregivers
- Symptom, distress, and functional status management (e.g., pain, dyspnea, fatigue, sleep disturbance, mood, nausea, or constipation)
- Exploration of understanding & education about illness and prognosis
- Clarification of [anticancer] treatment goals
- Assessment and support of coping needs (e.g., dignity therapy)
- Assistance with medical decision making
- Coordination with other care providers
- Provision of referrals to other care providers as indicated

Patients with advanced cancer should receive palliative care services, which may include referral to a palliative care provider.

→ May adapt to local settings, may brand it «Supportive & Palliative Oncology» Service
Palliative Care Interventions (PCIs)
Definable interventions as part of the specialist PC «package»

From the US Mass General RCT: documented PCIs

Few AdvCarePlan: expanded role of modern PC beyond just end-of-life care issues

1: Temel J et al. JCO 2016; Dec 28
2: Roeland EJ JCO 2017;1-3
### Palliative Care Interventions

**Pharmacological**
- (e.g. pleural pct)

**Procedural**
- (e.g. prognosis)

**Educational**
- (e.g. decisions)

**Counselling**
- (e.g. prompt list)

**Coaching, Empower**
- (e.g. behavioural)

**Psychological**
- (e.g. HCP network)

**Coordinative**
- ...

---

#### «Onco-Pivotal» Pall Interventions

#### «Palliative-Pivotal» Pall Interventions

- **Illness understanding**
  - (prognosis, mechanism, trajectory)

- **Symptom control**
  - (bio-psycho-social-spiritual)

- **Decision processes**
  - (cancer-specific Tx, nutrition, …)

- **Continuity of care Network**
  - (various HCP, home-out- inpat)

- **Care of family members**
  - (incl. premortal grief, coaching)

- **End of life preparation & care**
  - (family; double way, legacy, dying)

- **Spirituality**
  - (meaning, transcendence, ..)

---

Who should deliver which Palliative Care Interventions? Medical Oncologist Role different from Pall Care Specialist?

- Address symptoms
- Review illness understanding
- Addressing coping
- Cancer Tx: Effect, Decisions
- Cancer Tx: Specific tx plans
- EOL planning: DNR, Preferences
- Relationship and Rapport
- Engaging family members
- Medical complications

Figure 2. Elements of palliative care (PC) vs oncologic care visits at clinical turning points. EOL indicates end of life.
Multidimensional symptom management and communication including illness understanding, decisions, EOL and rehabilitation, patient and family. Integration of palliative interventions in multidisciplinary routine care.
In modern oncology, the double way (double awareness)\(^1\) is becoming increasingly important:

Dealing with finitude and preparation for end-of-life gives strength to live engaged and powerful with cancer.

## Illness & Prognosis understanding

### Prognosis-Talk

- Never say a median number! Ev. explain Surprise-Question\(^2\)
- If it goes (5%) bad – worst case (Complications, …): timespan A
- If it goes (5%) good – best case (modern oncology): timespan B

A: what do I then concrete? Preparation for End-of-Life
B: what do I then concrete? Continue to live, fight, enjoy

Normalization of ambivalence, of healthy denial & collusion
Acknowledgment of tough, emotional path; You do so well!
Concretization of professional help and continuity

The Communication-Intervention Prognosis-talk can (and must) be defined for mandatory (evidence-based) key elements

---

1. Epstein RM et al. JAMA Oncol 2016 Sep 9
Symptom Control Intervention(s): Key principles

Manage symptoms & syndromes multidimensional
- physical, emotional, intellectual, social, spiritual

Define Syndrome and risk factors
- Pain: incident, neuropathic, cognitive, emotional
- Cachexia: concurrent malnutrition, constipation
- Depression: concurrent delirium, dementia

Management by drugs, education, counseling, etc.
- always consider mechanism, ev. location
- always ask for impact of symptom on quality of life
- pharmacological management: Guidelines

Many symptoms are still poorly controlled
- insufficient access to drugs (e.g., opioids)
- no proactive screening
- non-specialized setting
- silent symptoms (fatigue, depression) neglected

Monitoring incl. coaching or symptom mgmt drugs or email alerts to HCPs

1: Cherny N Ann Oncol 2013;S11:xi7-13
2: Greco MT JCO 2014;32:4149-54
3: Berry DL JCO 2014;32:199-205
5: Basch E JCO 2016;34:557-65
7: Aapro M Ann Oncol 2014;25:1492-9
8: Sheinfeld Gorin S et al. JCO 2012; 30:539-547
Continuity of care Network Intervention

Prepare with the multiprofessional team a concrete care plan for community-based patients
- what symptoms are expected, what drugs needed
- who will assess patient, who gives drugs, how?
- who cares for the patients’ care needs?
- which phone numbers 1st – 2nd -3rd to call? 24/7

Care of family members Intervention

Discuss & acknowledge family members double role
- carer, advocate, „nurse“, coordinator,..
- own burden, grief work, prepare role after death

**Team work: what is the evidence?**

Systematic Literature Review

What is the quality of care decisions via the effect of MDTs on care management, % cases?

MDTs changed cancer mgmt by individual physicians in 2–52% of cases

Failure to reach a decision at MDT discussion: 27–52%

Decisions could not be implemented in 1–16%

Team decisions are made by physicians, using clinical information. Nursing personnel do not have an active role.

Patient preferences are not discussed

Time pressure, excessive caseload, low attendance, poor team-working, lack of leadership

→ lead to lack of information & poorer decision-making.
Conclusions

Patient needs are often underestimated and require proactive assessment in daily care.

Palliative interventions include pharmacological, procedural, communicative, coordinative, educational, and counseling and shall be delivered both by oncologists and PC Specialist.

Teamwork demands a passion to understand thinking and approach of other professionals/disciplines.

Palliative needs-related sessions at Preceptorship:

- Needs → PRO vs CRO → KJ S1
- Integration Oncology & Pall Care → SK S7
- Communication (BBN, Fam, BO, DHD) → LT S5
- Advanced Directives → FS S3
- Fatigue → JA S2
- Pain → JW S5
- Delirium, Dyspnea, Ascites → JW S6
- Cachexia → JA/FS S6
- Coordination Pall Networks incl. Oncol → JW S3
- Collaboration nurses & doctors → AY S6
- Planning, organization, pt mgmt EOL → SK S3
Fragen zum Unterstützungsbedarf (Supportive Care Needs Survey – SCNS-SF34-G)

Wir möchten Gern erfahren, ob und in welchem Ausmaß Sie Unterstützung beim Umgang mit verschiedenen Aspekten ihrer Erkrankung benötigen. Bitte geben Sie dazu für jeden der unten aufgeführten Aspekte an, ob sie während des letzten Monats Unterstützung benötigten. Kreuzen Sie bitte die Antwortmöglichkeit an, die am besten Ihr Bedürfnis nach Unterstützung beschreibt.

Während des letzten Monats: Wie groß war Ihr Unterstützungsbedarf im Hinblick auf…

1. Schmerzen
2. Müdigkeit und Erschöpfung
3. Unwohlsein (meiste Zeit des Tages)
4. Arbeit im Haushalt
5. Erledigung von Alltagsangelegenheiten
6. Angst
7. Niedergeschlagenheit oder Depression
8. Traurigkeit

Lehmann C, Koch U, Mehnert A. Validation of the German version of the Short-form Supportive Care Needs Survey Questionnaire (SCNS-SF34-G). Supportive Care in Cancer, 2012
Evidence of Palliative Care: specialized teams

- **US Lung Cancer** (Temel, NEJM 2010) QoL, Depression, Survival
- **US Lung & non-crc GI** (Temel, JCO 2016) QOL Lung wk 12/24, Gl wk24 Prognostic awareness
- **US Hemonc trspl.** (El-jawahri JCO 2016) Qol wk 2
- **Canadian** (Zimmermann, Lancet 2014) QoL, EOL burden
- **ENABLE I, II, III** (Bakitas, JCO 2015) QoL Pat & Caregiver, Survival
- **Japan** (Nakajima JPSM 2014) Communikation, QOL
- **Denmark** (Groenvold, Pall Med 2017) negativ (Intensity PC too low)
- **Italy** (Franciosi ESMO 2016) negative (contamination?)
- **Italy Pancreas** (Maltoni, Eur J Cancer 2016) QoL, aggressive EOLC
- **US** (Ferrel, JPSM 2015) Family QoL, Survival
- **Japan** (Murakami BMC Pall 2015) Survival
- **England** (Higginson Lancet Resp 2015) Qol, Survival
### Integration of PC into cancer care: where were the RCTs made?

<table>
<thead>
<tr>
<th>Source</th>
<th>Intervention</th>
<th>Control</th>
<th>Setting</th>
<th>Instrument</th>
<th>Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>High risk of bias</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Balintas et al.</td>
<td>72</td>
<td>83</td>
<td>Home</td>
<td>FACIT-Pal</td>
<td>Cancer&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Clark et al.</td>
<td>54</td>
<td>63</td>
<td>Ambulatory</td>
<td>FACT-6</td>
<td>Cancer&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Given et al.</td>
<td>53</td>
<td>59</td>
<td>Home</td>
<td>SF-36</td>
<td>Cancer&lt;sup&gt;c&lt;/sup&gt;</td>
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<tr>
<td>McCorkle et al.</td>
<td>36</td>
<td>56</td>
<td>Ambulatory</td>
<td>FACT-6</td>
<td>Cancer&lt;sup&gt;d&lt;/sup&gt;</td>
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<tr>
<td>Northouse et al.</td>
<td>69</td>
<td>65</td>
<td>Ambulatory</td>
<td>SF-36</td>
<td>Cancer&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Sidebottom et al.</td>
<td>79</td>
<td>88</td>
<td>Hospital</td>
<td>MLHFQ</td>
<td>Heart failure</td>
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<tr>
<td>Wong et al.</td>
<td>43</td>
<td>41</td>
<td>Home</td>
<td>MQOL-HK</td>
<td>Heart failure</td>
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<tr>
<td>Subtotal (&lt;i&gt;r^2 = 97.4%, P = .000&lt;/i&gt;)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Low risk of bias</td>
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<td></td>
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<tr>
<td>Balintas et al.</td>
<td>108</td>
<td>97</td>
<td>Home</td>
<td>FACIT-Pal</td>
<td>Cancer&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Higginson et al.</td>
<td>42</td>
<td>40</td>
<td>Ambulatory</td>
<td>EQ5D</td>
<td>Mixed&lt;sup&gt;g&lt;/sup&gt;</td>
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<tr>
<td>Rumsans et al.</td>
<td>47</td>
<td>49</td>
<td>Ambulatory</td>
<td>Spitzer</td>
<td>Cancer&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Temel et al.</td>
<td>60</td>
<td>47</td>
<td>Ambulatory</td>
<td>FACT-L TOI</td>
<td>Cancer&lt;sup&gt;h&lt;/sup&gt;</td>
</tr>
<tr>
<td>Zimmermann et al.</td>
<td>140</td>
<td>141</td>
<td>Ambulatory</td>
<td>FACT-SP</td>
<td>Cancer&lt;sup&gt;i&lt;/sup&gt;</td>
</tr>
<tr>
<td>Subtotal (&lt;i&gt;r^2 = 0.0%, P = .500&lt;/i&gt;)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unclear risk of bias</td>
<td></td>
<td></td>
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<tr>
<td>Bekelman et al.</td>
<td>172</td>
<td>180</td>
<td>Home</td>
<td>KCCQ</td>
<td>Heart failure</td>
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<tr>
<td>Grudzen et al.</td>
<td>39</td>
<td>30</td>
<td>Hospital</td>
<td>FACT-6</td>
<td>Cancer&lt;sup&gt;i&lt;/sup&gt;</td>
</tr>
<tr>
<td>Northouse et al.</td>
<td>198</td>
<td>104</td>
<td>Ambulatory</td>
<td>FACT-6</td>
<td>Cancer&lt;sup&gt;k&lt;/sup&gt;</td>
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<tr>
<td>Subtotal (&lt;i&gt;r^2 = 33.3%, P = .223&lt;/i&gt;)</td>
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<td></td>
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<td></td>
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<tr>
<td>Overall (&lt;i&gt;r^2 = 94.8%, P &lt; .001&lt;/i&gt;)</td>
<td></td>
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</tbody>
</table>

Verheissungen auf das «Wundermittel», gepaart mit der Schwierigkeit als Onkologe Voraussagen über das Ansprechen zu machen können (?) frühe Vorbereitung aufs Lebensende behindern

Aber: wahrhaftige Information reduziert Hoffnung nicht

Optimistisch geprägte versus weniger optimistische Aussagen können Einschätzung von Patient über die Compassion des Arztes und Kompetenz (Wahl als primary oncologist) beeinflussen

Weniger wenn eine (wirklich ) schlechte Nachricht überbracht werden muss

→ Optimismus, resp. konkrete Hilfestellungen sind wichtig: z.B. EOL Preparation

1: Tanco K et al. JAMA Oncol 2015;12:176-83  
2: Tanco K et al. Oncologist 2018;23:375-82
Conceptual model of palliative care delivery based on provider expertise
Another SLR on Teams

Teams improved screening use and reduced time to follow-up colonoscopy

Discussion of cases within MDTs improved planning of therapy, adherence to pre-operative assessment, pain control, and medications

No convincing evidence
- that MDTs affect patient survival or cost of care,
- how or which MDT processes and structures were associated with success

Oncologists shall deliver which topics of specialized PC?

966 PC service items as candidate elements of primary PC for pts with advanced cancer or high symptom burden. Modified Delphi by 31 experts: importance, feasibility, scope within medical oncology practice.

Encourage oncologists to deliver Pall Care
### Processes of Palliative Care Programmes at ESMO Designated Centres

#### Delivery of primary palliative care by outpatient oncologists

- Routine symptom screening available in oncology clinics: 118 (78)
- Proportion of patients with documented prognostic/illness understanding, median (IQR): 60 (25-80)
- Proportion of patients with goals of cancer treatment explicitly stated, median (IQR): 80 (50-95)
- Proportion of patients with end-of-life discussions documented in chart, median (IQR): 30 (15-50)
- Proportion of patients with advance care plans documented in chart, median: 20 (10-40)

---

**Oncologist do and want to provide palliative care interventions**

99 (65%) of ESMO-DCs: double-boarded physicians medical oncology & palliative medicine

Hui D, Cherny N, Latino N, Strasser F. Ann Oncol 2017 in press
## Interdependency in Teams

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>Two or more people contributing to a common product who each perform their own specific work relatively independently of each other and do not depend upon the work of the other to complete their task(^6)</td>
</tr>
<tr>
<td>Team</td>
<td>Two or more people who interact dynamically, interdependently, and adaptively to achieve a common valued goal, shared within the context of some larger group or organization(^7)</td>
</tr>
<tr>
<td>Interdependency</td>
<td>The situation in which people are mutually reliant on one another in order to complete their work and achieve their goals(^15)</td>
</tr>
<tr>
<td>Teamwork</td>
<td>The knowledge, behavioral skills, and attitudes that team members use to manage these interdependent tasks(^14)</td>
</tr>
</tbody>
</table>