AT VÆRE PÅRØRENDE TIL EN HJERTEPATIENT

AARHUS
UNIVERSITET
SCHOOL OF BUSINESS AND SOCIAL SCIENCES
PSYKOLOGISK INSTITUT

HELLE SPINDLER
LEKTOR

28. MARTS 2017


tooopen.com


illustrations of.com #1047406

PÅRØRENDE = SOCIAL STØTTE ?

Vi ved at social støtte er vigtigt og optimerer udbyttet ifbm. rehabiliteringsforløbet

Vi forstår de pårørende som en kilde til social støtte

Vi ved at patient og partner påvirker hinanden (Martire 2010)

Vi ved at patienter med partnere kommer sig hurtigere, har mindre brug for medicin og mindre risiko for død og ny hjertesygdom (Homish & Leonard, 2008).

Kan pårørende altid yde optimal social støtte?

Hvilke opgaver er det rimeligt at forvente af dem ifbm. patientens sygdom og rehabilitering?

Hvordan kan vi hjælpe dem med disse opgaver?

TEORETISKE OVERVEJELSER

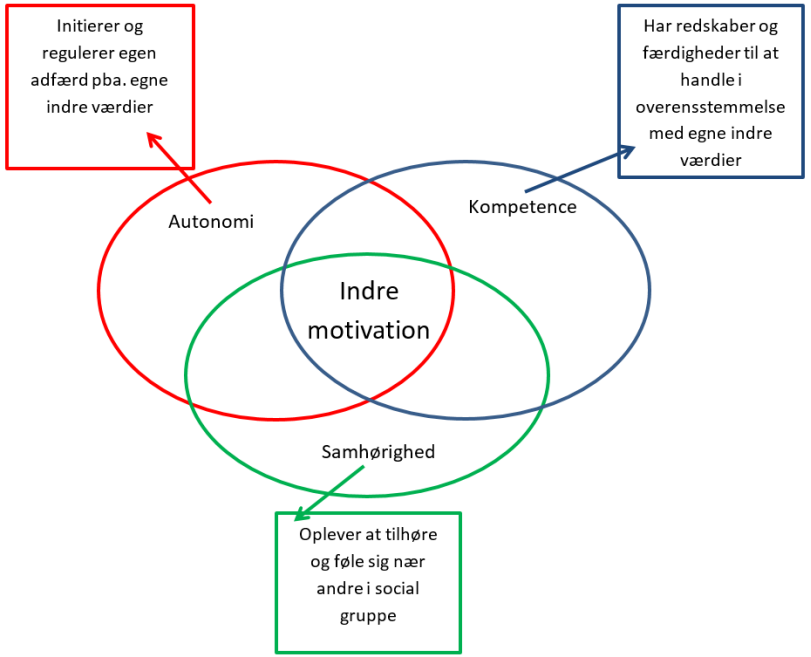
AARHUS
UNIVERSITET
SCHOOL OF BUSINESS AND SOCIAL SCIENCES
PSYKOLOGISK INSTITUT

HELLE SPINDLER
LEKTOR

28. MARTS 2017

Selvdetermineringsteorien

- En almenpsykologisk forståelsesramme for menneskelig motivation
- Mennesket har en iboende trang til at vokse
- Graden af vækst afhænger af i hvilken grad specifikke behov opfyldes
- Feedback en central mekanisme

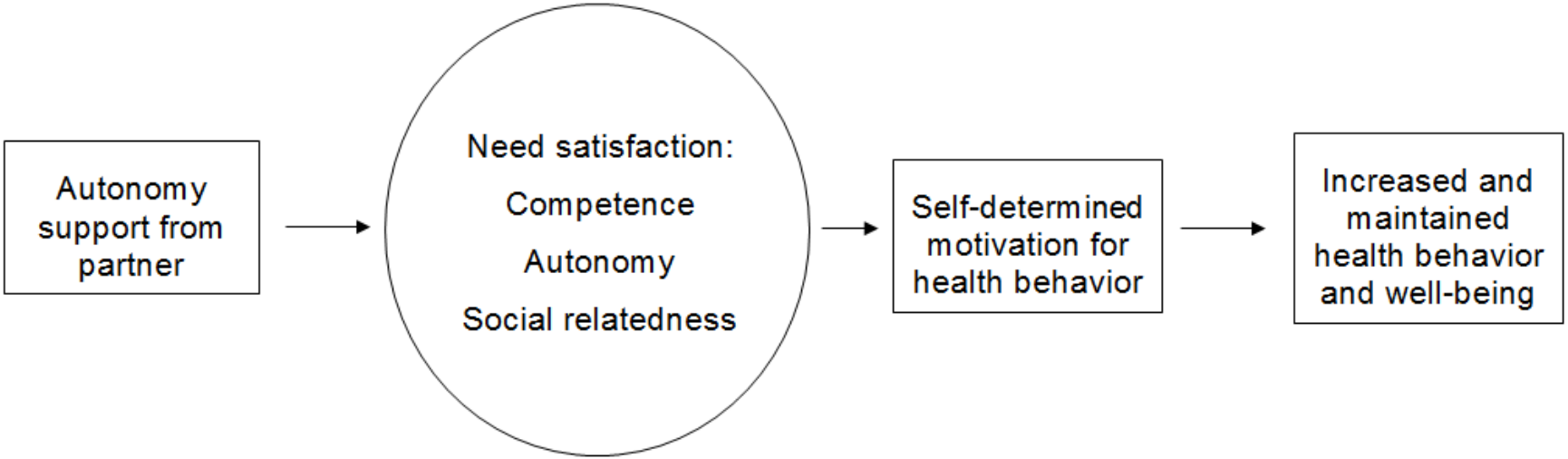


TYPER AF MOTIVATION

Motivationstype	Reguleringstype	Dyrker motion (eksempel)
Indre motivation	Indre	Af lyst og interesse
	Integreret	Fordi det er en vigtig del af personens selvforståelse at dyrke motion.
	Identificeret	Fordi det er sundt
	Introjiceret	Fordi det bør man
Ydre motivation	Ydre	For at undgå straf eller opnå belønninger
Demotiveret	Ingen	-

Partner: "I think that my husband doesn't exercise enough …But I would never exercise myself, so he can just turn around and say, well what is it that you do?".

SELVDETERMINERING HOS BEGGE PARTER



Patient: “Just as it is with cooking, for example, it's great that I go do the shopping and then stand there making a healthy meal, but if it just happens to be a day when he is supposed to cook, he just doesn´t do it and then it´s nine o'clock or something, and by that time no one really feels like cooking and we end up getting a pizza. So really, it kind of destroys the effort a little, right? And of course it´s ok to do it once in a while, but if it just becomes a new habit, well, that is what I have problems with.

Teorien om Interdependens (IT)

Ser dyaden som det centrale ift. adfærdsændringer

Interdependens = den indflydelse interagerende partnere har på hinanden

Udkommet er afhængigt af dyaden/parrets interaktioner, hvordan samarbejder de, har de konflikter, eller går de hver deres vej, når der skal ske forandringer.

IT integrerer patient og partners tanker, følelser, motivation og adfærd og hævder at dyaden skal forandre sig fra individuel, selv-centreret, til relations-centreret, eller ægtefælle-centreret motivation, dvs communal coping for at opnå et positiv udkomme (Lewis et al., 2006).

Fra jeg til vi!

EMPIRISKE FUND

AARHUS
UNIVERSITET
SCHOOL OF BUSINESS AND SOCIAL SCIENCES
PSYKOLOGISK INSTITUT

HELLE SPINDLER
LEKTOR

28. MARTS 2017

CARDIAC DISEASE AND ITS CONSEQUENCES ON THE PARTNER RELATIONSHIP

(review ift. MI, ICD og HF, Dalteg et al 2011)

Overbeskyttelse

Mangelfuld kommunikation

Bekymringer ift. intimitet og seksuelt samvær

Ændringer i rollerne i hjemmet

Tilpasninger til sygdommen

OVERBESKYTTELSE

Partneren overbeskytter patienten mht. aktiviteter og livsstilsændringer → konflikter

Pt's afhængighed af andre forstærkes af partnerens overbeskyttende adfærd

Partneren er bekymret pba. angst for nye hjertetilfælde

Patienten føler sig overvåget, vred, og frustreret

Partner: "It is what he chooses himself. He has been so indifferent [to the disease, suggested treatment, and lifestyle changes], which has provoked me very much. Even though I do feel terribly sorry for him, I am just so angry at him".

Partner: "Yes. But in the beginning he would not admit that he could not do these things. So, he would get angry and say, I'm not bloody handicapped! And then I would say, well, just go on then, and he would, but would have to give up a little later. And I did not do it to punish him. I just wanted to protect him."

COMMUNAL COPING – VI-TÆNKNING

Patient: "I was very tired, and he would rather not have that I was alone. So when we went out shopping, I had a kind of a tripod with me, a kind of a hunting chair. So while he rushed around, I sat there [all laugh]. And then he would come and I would say, "Isn´t there something cheaper?" [All laugh]." Researcher: "You surely know how to find solutions!" Patient: "But it worked because in just 14 days I was quite mobile again."

MANGLENDE KOMMUNIKATION

Parret har svært ved at kommunikere om følelser

De er bange for at gøre den anden bange, ked af det, mv.

Patienten ønsker ikke at gøre partneren ked af det

Partnere ønsker ikke at gøre de anden ked af det, men samtidig også angst for at provokere ny sygdom

Patient: "...I have begun to say much more yes, I feel well, when I do not feel well and find it easier ... because I don't have to explain so much ... more and more I notice that I both say and do not say exactly as it is."

Partner: "One goes around and thinks all the time and asks sometimes how it feels... I see it on her but I don't think that she tells me because she doesn't want me to worry. "

BEKYMRINGER IFT. INTIMITET OG SEKSUELT SAMVÆR

Seksuel aktivitet forbindes med forhøjet risiko for nyt hjerteanfald (særligt ICD)

Angsten kan forplante sig og generaliseres til alle former for intimitet → en vigtig del af relationen undgås/misligholdes

Partner: "I think the [ICD] almost affected me worse than it did him . . . I was just so tense [before sex] that I had to have a couple of glasses of wine, and I was more relaxed. The thought of it going off kind of got pushed to the back of my mind and everything went okay then."

ROLLEÆNDRINGER I HJEMMET

Partneren overtager flere opgaver i hjemmet.

Partneren føler skyld ift. at lade patienten klare fysisk krævende opgaver i hjemmet

Partnere føler sig frustrerede og angste, samtidig med deres livsudfoldelse bliver begrænset pga. patientens manglende kunnen, hvilket både stiller større krav, men også begrænser parrets aktive og sociale liv.

Partner:"I think it's hard. I know that there are good days and bad days and it is for everyone, but I think the days are getting harder and harder because it is the job I have, I have to be there and on my toes at all times. Then I come home, and I have to be there and on my toes but in a different way. In the beginning we went for walks and it was good to get out and get some exercise, but I have to admit, I just don´t have the energy to do it. I am tired when I get home. Well, I feel that we need some support and help, I really do."

TILPASNING TIL SYGDOMMEN

Kræver mange ændringer i hverdag og livsstil

For nogen skaber det stress og konflikt, for andre en følelse af solidaritet (communal coping)

Parrene søger og håber på "normalitet"

Over tid, og hvis parrene er i stand til at "finde hinanden" giver dette mulighed for psykologisk vækst

- Sygdommen bragte dem tættere sammen
- De fandt ny mening og fandt hinanden igen

Et studie fandt at partnerens angst, gjorde det sværere at tilpasse sig sygdommen

Partner: "If I had been built in such a way that I would find this good, well, salad and such, well, then we would not have been too fat in the first place, right? But what the hell, it is connected. And therefore there is no use in pretending that you just think, let's just eat this and that. We are being forced to do it, and then you just have to do it, but I am absolutely not amused."

PARTNERENS PSYKISKE TILSTAND

At være partner/caregiver kan være hårdt psykisk

Caregiver burnout (mangler mere viden ift. hjertepårørende)

Et hollandsk studie sammenlignede ICD patienter og deres partnere:

Partnerne havde højere grad af angst end ICD patienterne.

Skyldtes ikke kun partnerens personlighed, men også patients kliniske karakteristik (sekundær profylakse). (Pedersen et al., 2009)

Researcher: “So you still have the anxiety?” Partner: “Yes, I do. Even at night, I can still see it, for example the time he got ill. That memory just keeps creeping up on me.” Researcher: “Do you see that image in your head at night?” Partner: “Yes, I do, because at that time I was quite sure he was dead. And then the staff said that the last thing he had said was, give them my love.”

OPSUMMERING

Højt niveau af angst hos partneren skaber konflikter, hæmmer kommunikationen

Manglende kontrolfølelse hos partneren fremprovokerer konflikter pga. overbeskyttelse

Parterne er ikke i stand til at tale sammen om hvordan de har det, dvs. de er i risiko for at skabe større afstand i relationen

Dette kan yderligere forværres af angsten for fysisk intimitet (seksuelt samvær)

Det kan være svært at skulle bytte roller i hjemmet, partneren kan føle sig skyldig over ikke at kunne gøre alt (curlingpartner?), udmattende at påtage sig hele ansvaret hele tiden.

Ændringer i hverdagsliv og livsstil er svære, kræver "communal coping"

– hvis parrene lykkes kan det give positive effekter, men hvis ikke kan relationen kuldsejle.

Partner: "No. Well, there was a moment when all hell broke loose, how was it again... She came home and told me proudly that she now could run for ten minutes straight on the treadmill at the center. And I just could not relate to that, well. That is, it was just so little. In fact, it was actually so that I thought she said something and I just laughed at her. Or something like that. Well, I just felt this message I got was so far out. But she got fairly angry about it. And felt I was putting her down, right? But, the idea that you cannot just set the treadmill to 2 km/hour and then go for ten minutes, and to almost be unable to do so..."

INTERVENTIONER

AARHUS
UNIVERSITET
SCHOOL OF BUSINESS AND SOCIAL SCIENCES
PSYKOLOGISK INSTITUT

HELLE SPINDLER
LEKTOR

28. MARTS 2017

INTERVENTIONS TO IMPROVE PSYCHOLOGICAL OUTCOMES IN CAREGIVERS OF HF PATIENTS

(Evangelista et al., 2016)

Psykoedukation ved fysisk fremmøde, som det indledende tiltag

Follow-up sessioner

- Fremmøde
- Hjemmebesøg
- Telefonopkald
- Telemonitorering

Støttegrupper

Ledet af sygeplejerske eller en fra behandlingsteamet

Tidsramme: 1-12 måneder

Deltagere: Nogle kun partnere, andre begge parter i dyaden.

RESULTATER:

Ikke konklusive eller entydige.

Nogle havde effekt - andre ikke

"The interventions can also be defined as complex warranting a tailored person-centered approach rather than being completely standardized."(Evangelista et al.,2016)

PARTNERS FOR LIFE PROGRAM (SHER ET AL., 2014)

En par-intervention med fokus på at reducere risiko for fornyet hjertesygdom.

Fokus var bedring af livsstilsændringer og behov for bedre støtte fra det sociale netværk.

Målet var holdbare adfærdsændringer (motion, mad, medicinadhærens) og reduceret risiko for hjertesygdom.

Nyskabende, da man ikke bare bad partnerne deltage i patientens program, men lod dem blive integrerede dele af interventionen. De fik deres egen specifikke rolle og handlerum

Undersøgelsen sammenlignede par med patienters udkomme, og fandt positive resultater for alle par sammenlignet med patienterne.

TAKE HOME MESSAGE

Brug for nytænkning og partner-orienterede interventioner, hvor det sikres at:

- Dyaden udgør kernen i den sociale støtte
- Partneren får opmærksomhed mhp. at håndtere angst, kontroltab, coping
- Der er fokus på at identificere evt. psykiske problemer – også hos partneren
- Partneren involveres/integreres i patientens intervention (participation → motivation), ligeværdige partnere
- Parret støttes i at kommunikere bedre (især emotionelt), få sat ord på det der er svært, få bedt om hjælp, få sagt til og fra.
- Parret støttes i at arbejde henimod communal coping.

Tak for jeres opmærksomhed

hellesp@psy.au.dk

AARHUS
UNIVERSITET