QUALITY OF LIFE OPTIMIZED PATIENT MANAGEMENT IN ONCOLOGY

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MAMMA-CARCINOMA-PATIENT

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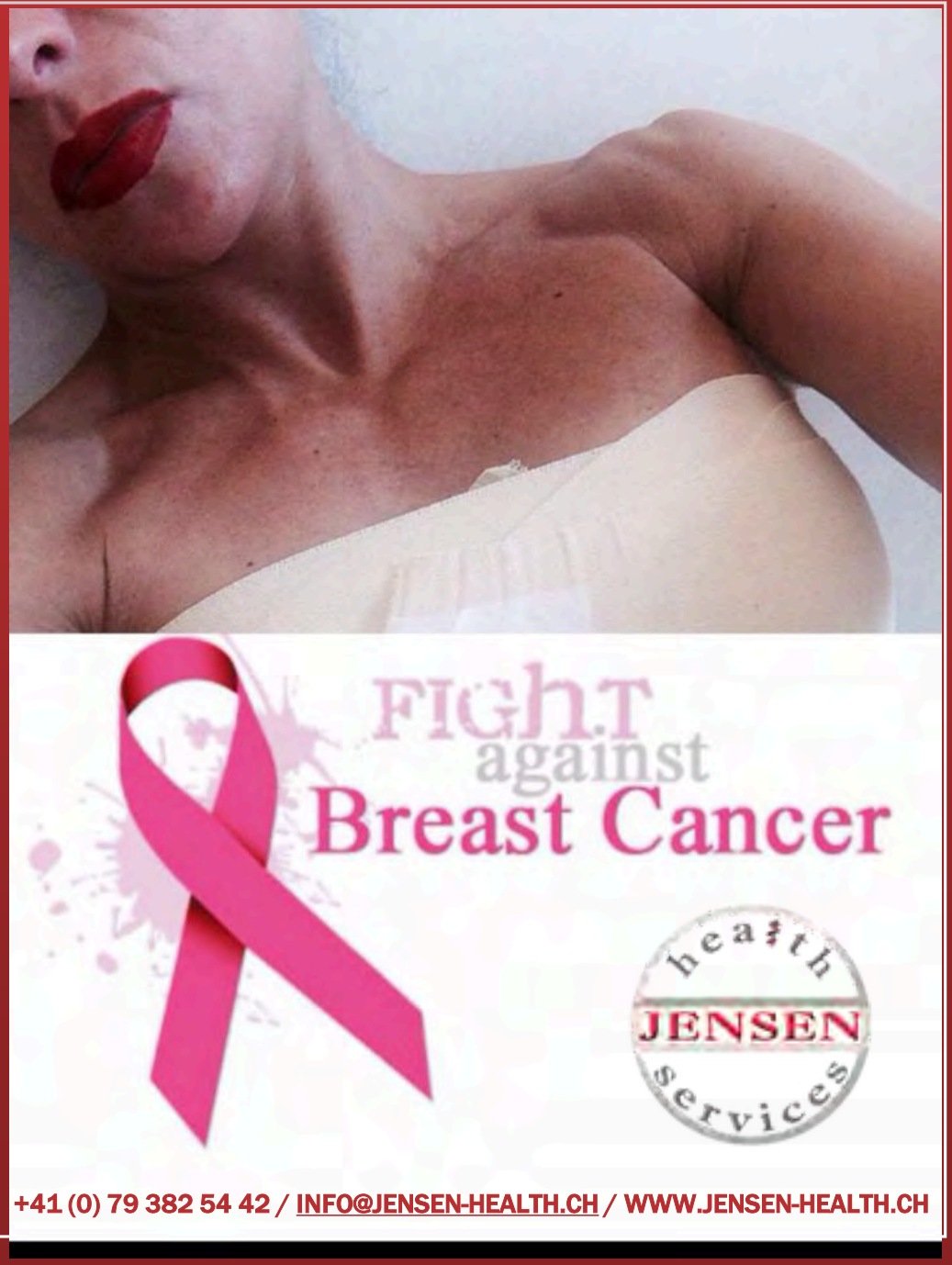

GENERAL CONSIDERATIONS (1):

WHAT IS QUALITY OF LIFE AND HOW IS IT MEASURED?

For the patient – to remain HUMAN

WHAT IS QUALITY OF LIFE

WHO: "state of **physical, emotional, mental, social** and **sexual** well-being and not just the absence of disease, dysfunction or ailments."

- Physical and cognitive fitness / performance
- Emotional and social competence and fulfillment
- Intact body sensation, sexual performance and pleasure (orgasm / arousal / erection ability) - BRSEF / BRSEE

HOW IS QUALITY OF LIFE MEASURED?

- Short Form 36 (SF-36)
- European Organisation for the Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30)
- Functional Assessment of Cancer Therapy-General (FACT-G)
- Visual Analogue Scale-Cancer (VAS-C)
- Hospital and Anxiety Depression Scale (HADS)
- Profile of Mood States (POMS)
- Rotterdam Symptom Checklist (RSCL)

Oncologist. 2002;7(2):120-5.

GENERAL CONSIDERATIONS (2)

PATIENT- VS MORBUS - MANAGEMENT

For the patient – to remain HUMAN

- The oncopatient is still a person who, after leaving the hospital, is entitled to a full life, with the desirable body, mind and personality
- How is the medical treatment implemented?
- How far does medical treatment support the dignity of a human being? And how does she disregard her?
- Where is the line between effective safety (recurrence prevention, side effects that must be taken into account) and quality of life-sparing treatment (without affecting the effect)

GENERAL CONSIDERATIONS (3)

PATIENT- VS MORBUS- MANAGEMENT

For the patient – to remain HUMAN

- Endpoints: healing / curative, life extension, ... Life quality?
- Surgical treatment of the paliative patient - where is the limit?
- Motivation to fight - when treating a colleague / when treating a patient

Where is the man behind the patient?

QUALITY OF LIFE - RELEVANT PARAMETERS

For the patient – to remain HUMAN

RELEVANT AREAS

CHIRURGIE	ONKOLOGIE	RADIOONKOLOGIE	DIAGNOSTIK
Body feeling	Performance	Function	
Sexuality (Breast)	Sexuality (Libido)	Compromising further (Breast) treatment (If the skin is too damaged, a quality of future breast reconstruction and / or quality maintenance of previously performed breast reconstruction is compromized)	Misfindings that lead to unnecessary clarification investigations
Optic (Brust)	Toxicity (avoidable long-term-side- effects)	avoidable long-term-side- effects (capsular contracture)	
Function (Prostata)	Body feeling (toxicity-related)	Compromizing further treatment Prostata (performing Conduit is compromized, if rectum is damaged)	

MAMMAKARZINOMMANAGEMENT
STANDARD VS INDIVIDUELL

For the patient – to remain HUMAN

STANDARD

- Mamma-amputation without Skin&Nipple-sparing
- Chemo-treatment WITH Anthracyclins, without consideration of proven Risk/Benefit in particular case
- Radiotherapy of the cheast wall aftera breast reconstruction with silicone a./o. taking into account irradiation of a heart
- Lack of education about sexual behavior during chemo (toxic excretions of chemotherapeutic agents and mitigation relevant side effects) and unaesthetic compression bra
- Follow-up diagnostics without regard to previous recording and corresponding causality assessment

INDIVIDUAL

- Skin & Nipple-sparing mammary amputation, with quick-cut / biopsy ex-tempore resection detection
- Chemo treatment option with critical review of benefit (meaningful clinical trials comparing / comparing with / without benefit) anthracyclines
- Irradiation ONLY axillary and clavicular WITHOUT chest wall (after breast reconstruction with silicone)
- Education on (vaginal) excretions of the chemotherapeutic agents and appropriate adaptation of the sexual behavior (inter alia, use of the condom, in the peak phase, avoidance of mucosal contact); aesthetic compression bras
- Follow-up diagnostics with careful analysis of all previous recordings and subsequent causality evaluation and reporting

APPEAL TO COLLEAGUES – SURGERY
MAMMA-CARCINOMA

For the patient – to remain HUMAN

- It still applies the principle "Primum non nocere" - “primarily not hurt”!
- Skin sparing as a goal: Later reconstruction, after the skin coat is gone, is not aesthetically acceptable, expansion of pre-irradiated skin is only partially possible. Risk of residual glandular tissue presence and thus residual recurrent risk is minimized by experience / competence of the surgeon and quick-cut / biopsy ex-tempore diagnostics. In addition, the potential risk of recurrence is much smaller than the immediate reduction in quality of life with the following comorbidities (including depression).
- Nipple sparing as a goal: Alternative is never so aesthetic and the function is lost with foreign tissue. By contrast, the feeling of touch / function in nipple sparing is not impaired in every woman (it's worth trying to save her own mamilla). Finally, she plays a major role in erotics and thus in the "woman-feeling", very important for the self-esteem of a breast-operated woman, where it is particulary this "woman-being" feeling, which suffers greatly
- Necrosis management: is conservative or surgical treatment effective? Necroses are known to be due to lack of vascular network and are often well-defined; their surgical treatment not only creates a new scar, but also a a renewed necrosis risk in the same region and re-surgery. Eventually, the Breast transforms into a scarred skin surface with greatly reduced volume – you are losing the breast. Here the careful examination is necessary. By contrast, conservative treatment offers the opportunity for a regular wound healing process and successive replacement of necrosis by new tissue, without additional tissue / Breast loss
- Be honest in patient education about risks and long-term consequences, especially in the case of the latissimus transplant that later leads to painful permanent movement limitations, yet this is often kept secret or "talked away".

Think about whether you (in private life) would find such a breast attracting / would like to have a sexually performing partner - and make the best out of it - as for yourself or for your own partner!

APPEAL TO COLLEAGUES - ONCOLOGY

For the patient – to remain HUMAN

- Here, too, the principle "Primum non nocere" still applies - “primarily do not hurt"!
- Examine absolute need for highly toxic agents (including doxorubicin) in each individual case. These are in many cases not scientifically acceptable and provide unnecessary serious toxic side effects. The effect of the high toxicity on overall life expectancy has to be checked.
- Check current scientific study results instead of automatically tracking the "standards" that were set at some point. This is currently rarely done. 90% of patients with the same tumor type (e.g., HER (+)) receive the same chemo-combination.
- Inform the patient (in, for her understandable, language) about the treatment options and all pros and cons and let her co-deciside, as far as possible.
- Clarify the patient about the side effects as well as excretions (and thus side effects for the children / partner). Genital area is still a taboo; side effects that are associated with it (as well as dryness / libido) and toxic (vaginal) excretions, which can affect especially the sexual partner are often concealed. It is your duty to inform the patient about it (also about the possibilities of protection)!
- CR prostate carcinoma: CAVE Doxitaxel (Risk / Benefit). Genetic testing to predict efficacy of the abiraterone / enzalutamide.

APPEAL TO COLLEAGUES - RADIOONCOLOGY

For the patient – to remain HUMAN

- Again, the principle "Primum non nocere" still applies - “primarily do not hurt"!
- Heart irradiation as a side effect and thus heart attack / death risk can not be ruled out even with the latest methods, even if it is claimed otherwise. Thus, the co-irradiation of the chest wall is, as high-risk, to narrow down to absolutely essential, and not, as today, as a non-questionable standard treatment!
- Skin dissolution and open wounds are often concealed in advance; only when they occur does it say "this happens frequently". If the skin of the chest wall dissolves after unnecessarily performed chest wall irradiation and thus makes subsequent reconstruction impossible or compromises an already performed reconstruction (because the dissolved skin can no longer support the reconstructed contents), it is of (even criminal) relevance to the radiologist (Malpractice / body harm) if the patient dares to pursue this path
- Adjusts the radiation dose and irradiation range to the effective local recurrence risk! This is often not done. Often, although recommended, the separate treatment protocols for the mastectomized patients are not implemented, but only those for St.Post.Breast-conserving therapy (where a correspondingly higher risk of recurrence than in the case of complete mastectomy is to be expected), applied to all patients. concerning both the irradiance and the irradiation region. Chest wall irradiation benefit in amputated breast and thus the justification for the associated risks (including myocardial infarction!) Is currently scientifically highly contested! Especially contraindicated with existing silicone implant!
- Prostate cancer: effects on the rectum and possible impairment planned conduit surgery

APPEAL TO COLLEAGUES- DIAGNOSTIC

For the patient – to remain HUMAN

- Again, the principle "Primum non nocere" still applies - “primarily do not hurt"!
- Check all previous data, their relationships and causality for the latest findings before you issue the report. Your report may be the first step into a (new) treatment
- Remember that your report can be consequential - from the need for action / the need for re-treatment (if the new finding needs to be treated) to the (in extreme cases) patient's depression / suicidal tendencies. If such a finding, due to negligent prior examination failure, shows to be inconspicuous or previously known, and the patient is unnecessarily treated and / or the patient experiences unnecessary avoidable harm, the responsibility lies with you.
- Do not expect that the next therapist (oncologist or other radiologist) will interpret your report correctly, but do your part carefully
- Again, the principle applies - do it as it is for yourself or for your own family member!

APPEAL TO THE NURSING-TEAM (MAMMA-CARCINOMA) (RADIO)ONCOLOGY)

For the patient – to remain HUMAN

ONCOLOGY

- Clarify the patient about the side effects as well as excretions (and thus side effects for the children / partners). Genital area is still a taboo and side effects associated with it (as well as dryness / libido) and toxic (vaginal) excretions, which can affect especially the sexual partner are often concealed. It is your duty to inform the patient about it (also about the possibilities of protection)!
- Suppor women, as well as those who can care for their skin (which often suffers from chemo)

RADIOONCOLOGY

- Consider the aesthetics of anatomical markings of the area to be irradiated. Remember that you have a woman in front of you, who still wants to / may / should be attractive and beautiful- in front of the partner, in the swimming pool and, above all, in front of herself - also every day during the irradiation-period.
- Clarify the patient about all expected side effects - skin dissolution (!), Anemia, skin care during and after the irradiation

TAKE HOME POINTS

For the patient – to remain HUMAN

WHAT CAN I / COLLEAGUE DO?

- Ask yourself «can I imagine my quality of life under given conditions» and «what can I optimize to improve it?»
- I help the future patient with the observation of today's patient to improve the knowledge in the future:
- (before / after comparison): the baseline post-therapy evidence of (deterioration in) quality of life - (1) cardio / pulmonary exercise test, (2) performing well-known questionnaires (before / after) (2) cognitive abilities , (3) physical perception, (4) sexual performance & enjoyment, (5) emotional fulfillment
- Studies comparing efficacy and safety With / without toxic chemotherapeutic agents (including antracyclines) - to refrain from toxic agents in the future when no significant benefit has been demonstrated
- Due to current knowledge, prevention of known side effects / toxicity / irreparable suboptimal surgical / radiological / solutions I am helping today's patient

WHAT CAN THE SYSTEM DO BETTER?

- Quality of life maintenance as a KPI
- Identify the therapeutic measures that enhance quality of life (for example, nipple sparing, narrowing the indications / double test for chest wall radiation and use of highly toxic anthracyclines, use of biomarkers to optimize the use of chemotherapeutic agents)
- Creation of causality between the competence / experience and the optimization of the quality of life
- Quality of life Awareness training for staff
- Conduct more clinical trials that have primary endpoint quality of life
- More detailed tracking of therapeutic measures to determine their impact on the quality of life and to limit the use of the non-beneficial

FURTHER READING

For the patient – to remain HUMAN

- Balazs&al, Perm J. 2015 Spring; 19(2): 48–79. «Breast Cancer Survivorship: A Comprehensive Review of Long-Term Medical Issues and Lifestyle Recommendations" – bis 2 Jahrzehnten post-Dg (Anthrazykline) und sehr häufig (30% Herzversagen unter Cyclophosphamide, u.a.)
- Tessler Lindau & al, CA Cancer J Clin. 2016 May; 66(3): 241–263. "Physical Examination of the Female Cancer Patient with Sexual Concerns: What Oncologists and Patients Should Expect from Consultation with a Specialist" – u.a. Vorbeugungsplan-Entwicklung inkl. Vaginaldilatation für Vorbeugung der post-Radiation Vaginalstenose
- Harris & co, J Clin Oncol. 2016 Apr 1; 34(10): 1134–1150. «Use of Biomarkers to Guide Decisions on Adjuvant Systemic Therapy for Women With Early-Stage Invasive Breast Cancer: American Society of Clinical Oncology Clinical Practice Guideline"
- Saleh & co, Res Rep Urol. 2015 7: 19–33: Management of erectile dysfunction post-radical prostatectomy
- Haoheng & Wang, Trans Androl Urol 2013: The science of vacuum erectile device in penile rehabilitation after radical prostatectomy

RELEVANT SUPPORTING LINKS

For the patient – to remain HUMAN

For oncology:

- Information about the respective excretions of the drug - Department Medical Information of the respective manufacturer

For care:

- Aesthetic compression-bras: www.schockabsorber.com / www.schockabsorber.de
- Care cream against chemo-treatment-induced dryness of the vagina / anus
- Lubricants that, despite the chemo treatment-related, dryness of the vagina / anus, should allow a pain-free sexual intercourse
- Wigs / Make-up / Permanent Makeup / Nipple Tattoos - various providers
- Vacuum pump for non-drug treatment of erectile dysfunction and penile rehabilitation

CONCLUSION

For the patient – to remain HUMAN

MAKE IT YOUR PATIENTS -

AS FOR YOURSELF / OWN FAMILY!

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