

# Supporting families in palliative care

*Dr. Maysoon S. Abdalrahim*

*Modified by Amer Hasanien RN MSN PhD*

## Family-centered palliative care



## Family-centered palliative care


- Most often, families in palliative care do consist of spouses, and their children.
- People unrelated by blood or marriage may function as family.
- The family is a group of individuals linked in ways that are constantly interactive and mutually reinforcing.
- Palliative care programs are based on the principle that the family is the unit of care.

- In practice, the family is viewed as a group of individuals who can either provide helpful or resist efforts to deliver care.



## Family-centered palliative care

- ▶ Best outcomes are achieved if appropriate interventions are directed at the family members
- ▶ Family look to health professionals to provide quality care to the patient. They expect health professionals to meet their own needs for information, emotional support, and assistance with care.

- 
- ▶ Research suggests that the most effective way to support family caregivers is to help them be in their caregiving role rather than to focus on personal needs.

## The transition of fading away



## The transition of fading away

- ▀ Usually, transitions are initiated by changes, by the start of something new.
- ▀ Bridges suggested that most transitions actually begin with endings. This is true for families living with serious illness in a loved one.

“fading away.”

- ▶ The transition of fading away for families facing terminal illness began with the ending of life as they knew it.
- ▶ The awareness triggered when family members see a change in the patient’s body or physical capacity (weight loss, extreme weakness, lack of mobility, or diminished mental capacity).

## The transition of fading away

- ▶ The 7 dimensions to transition of fading away:
  1. Redefining
  2. Burdening
  3. Struggling with paradox
  4. Contending (يكافح، يناضل) with change
  5. Searching for meaning
  6. Living day by day
  7. Preparing for death.
- ▶ The dimensions are interrelated and linked

## Redefining

- ▶ Redefining involves a shift from “what used to be” to “what is now.”
- ▶ Patients began to implement alternatives once they realized that their capacities were seriously changing.

***“I just can’t do what I used to. I finally had to accept the fact that the seizures made it unsafe for me to drive.”***



- ▶ Patients accepted their limitations with much sadness and a sense of great loss.
- ▶ Their focus narrowed, and they began to pay attention to details of everyday life that they had previously ignored
- ▶ They often become more spiritual



## Redefining

- Patients who were unable to redefine themselves despite the obvious changes in their capacity to do so ended up frustrated, angry, and feeling worthless.
- The family attributed the changes to the disease, not to the patient personally, and as a result, they were able to empathize with the patient.



## Redefining

- Patients' redefining focused on themselves, the changes in their physical status
- Family's redefining centered on their relationship with the patient. They consider alternatives and reorganized their priorities.

## Redefining

- ▶ When patients were able to redefine themselves, family will have easier time.
- ▶ But when patients were less able to redefine, they will reject or do not appreciate family support.
  - ▶ Family avoid talking about or doing anything that remind the patient of the changes
  - ▶ Family become frustrated and angry, although often they remained silent

## Burdening







## Burdening



- ▶ Patients feel they are a burden for their family
- ▶ They see themselves as purposeless and dependent
- ▶ The more patients redefined themselves, the more accurate they were in their perceptions of burdening.



## Burdening

- ▶ Most spouses acknowledged the “extra load” of caring for their dying partner, but indicated that they did not regard the situation as a “burden.”
- ▶ Spouses put aside their own distress so that it would not have a negative impact on the patient.
- ▶ They were energized by the patient's acknowledgment of their efforts and were inspired to continue on.

## Burdening

- ▀ Spouses of patients who were not able to redefine felt unappreciated, exhausted, and confessed to “waiting for the patient to die.”
- ▀ Types of burden:
  - ▀ physical burden: fatigue and physical exhaustion, sleeplessness, and deterioration of health.
  - ▀ Social burden encompasses limited time for self and isolation.
- ▀ Family expressed satisfaction with their caregiving.

## Burdening

- ▀ Finding effective ways to support family caregivers is critical,
- ▀ each family must decide what will actually be helpful for them. For some families, inpatient services during the last year of life may help relieve their burden, while other caregivers may experience feelings of guilt and increased stress because of worrying about the quality of care provided.
- ▀ Make resources and support readily available, even if they do not make use of them.

## Struggling with paradox

- ▶ The fact that the patient is both living and dying.
- ▶ For patients, the struggle focuses on wanting to believe they will survive and knowing that they will not.
- ▶ They did not want to “give up” but at the same time were “tired of fighting.”
- ▶ They wanted to “continue on” for the sake of their families but also wanted “it to end soon” so their families could “get on with their lives.”
- ▶ hoping for miracles

## Struggling with paradox

- ▶ Family struggled with a paradox of their own: they wanted to care for and spend time with the patient, and they also wanted a “normal” life.
  - ▶ They put their own life on hold. neglected their own needs.

## Contending with change

- ▶ Patients faced changes in their relationships with everyone they knew. They realized that life as they knew it would soon be gone.
- ▶ The greatest change that spouses faced was in their relationship with the patient. They coped by attempting to keep everything as normal as possible.



## Searching for meaning

- ▶ Seeking answers to help in understanding the situation.
- ▶ Patients tended to reflect on spiritual aspects, deepen their most important connections, and become closer to nature (????):
- ▶ Family concentrated on their relationship with the patient.
  - ▶ personal growth,
  - ▶ simply tolerating the situation.
  - ▶ some focused on spiritual growth



## Living day to day



- ▶ If patients were able to find some meaning in their experience, then family were better able to adopt an attitude of living each day.
- ▶ Patients who were unable to find much meaning in their experience, or who didn't search for meaning, focused more on "getting through it."

## Preparing for death

- ▶ concrete actions that would have benefit in the future, after the patient died.
- ▶ Patients work hard to teach or guide family members with regard to various tasks and activities that the patient would no longer be around to do.
- ▶ family concentrates on meeting the patient's wishes.



## في ما ورد عن بر الوالدين



قال تعالى : ( وإذ أخذنا ميثاق بني إسرائيل لا تعبدون إلا الله وبالوالدين إحسانا ) البقرة 83 والإحسان نهاية البر ، فيدخل فيه جميع ما يحب من الرعاية والعناية

عن عبد الله بن مسعود رضي الله عنه  
 قال: سألت النبي صلى الله عليه وسلم  
 أي العمل أحب إلى الله عز وجل؟ قال: ( الصلاة على وقتها )  
 قال: ثم أي؟ قال: ( الجهاد في سبيل الله )

## في ما ورد عن بر الوالدين

عن عائشة أم المؤمنين رضي الله عنه قال  
 رسول الله صلى الله عليه وسلم  
 ( دخلت الجنة فسمعت فيها قراءة قلت  
 من هذا؟ فقالوا: حارثة بن النعمان ) فقال  
 رسول الله صلى الله عليه وسلم ( كذلك  
 البر كذلك البر [ وكان أبر الناس بأمه ] )

■ وعن عبدالله بن عون: أن أمه نادته فأجابها فعلا  
صوته صوتها فأعتق رقبتين.

■ قال عبدالله بن عباس: كن مع الوالدين كالعبد  
المذنب الذليل للسيد الغليظ. وقال وهب بن  
منبه: بلغنا أن الله تعالى قال لعزير عليه السلام:  
بر والديك , فإن من بر والديه رضيت , وإذا رضيت  
باركت , وإذا باركت بلغت الرابع من النسل. وسئل  
الحسن عن الوالد والوالدة فقال: حق الوالد أعظم  
, وبر الوالدة الأزم.

■ قال حميد: لما ماتت أم أبياس بن معاوية: بكى ,  
ف قيل له: ما يبكيك؟ قال: كان لي بايان مفتوحان  
إلى الجنة , وأغلق أحدهما. قال عمر  
بن عبدالعزيز: لأبن مهران , لاتصاحب عاقاً, فإنه  
لن يقبلك وقد عق والديه. ( لأن حقهما أوجب حقاً  
منه عليه ). وقال علي رضي الله عنه: لو علم الله  
شيئاً في العقوق أدنى من [ أف ] لجرمه. وقال  
أحد السلف: من عق والديه عقه ولده.

■ عن الحسن البصري: أن رجلاً قال له: إني قد  
حججت وقد أذنت لي والدي في الحج.. فقال  
الحسن: لقعدة تقعدها معها على مائدتها أحب  
إلي من حجك. وعن منصور بن المعتمر كان يقال:  
للأم ثلاثة أرباع البر. وقال عروة بن الزبير: ما بر  
والديه من أحد النظر إليهما. وكان مورك العجلي:  
يفلني رأس أمه.

■ قال وهب بن منبه: أوحى الله تعالى إلى موسى  
عليه السلام: ياموسى وقر والديك , فإن من وقر  
والديه مددت له في عمره , ووهبت له ولداً يبره  
, ومن عق والديه قصرت عمره , ووهبت له ولداً  
يعقه. وقال ثابت البناني: أن رجلاً كان يضرب أباه  
في موضع , فقيل له: ما هذا؟ فقال الأب أتركوه ,  
فإني كنت أضرب أبي في هذا الموضع فابتليت  
بابني يضربني في نفس هذا الموضع. وعن اصبع  
بن زيد قال: إنما منع أويسا القرني أن يقدم على  
رسول الله صلى الله عليه وسلم بره بأمه.



► في حديث مسلم عن عمر رضي الله عنه قال: إني سمعت رسول الله صلى الله عليه وسلم يقول: (إن خير التابعين رجل يقال له أوبس وله والدة وكان به بياض فمروه فليستغفر لكم). فكان عمر بن الخطاب رضي الله عنه إذا أتى عليه أمداد أهل اليمن سألهم: أفيكم أوبس بن عامر حتى أتى على أوبس رضي الله عنه، فقال له: أنت أوبس بن عامر؟ قال: نعم. قال: من مراد ثم من قرن؟ قال: نعم. قال: فكان بك برص فبرأت منه إلا موضع درهم؟ قال: نعم. قال: لك والدة؟ قال: نعم. قال: سمعت رسول الله صلى الله عليه وسلم يقول: يأتي عليكم أوبس بن عامر مع أمداد أهل اليمن من مراد ثم من قرن كان به برص فبرأ منه إلا موضع درهم له والدة هو بها بر لو أقسم على الله لأبره، فإن استطعت أن يستغفر لك فافعل، فاستغفر لي، فاستغفر له، فقال له عمر: أين تريد؟ قال: الكوفة. قال: ألا أكتب لك إلى عاملها؟ قال: أكون في غبراء الناس أحب إلي، فلما كان من العام المقبل حج رجل من أشرفهم فوافق عمر فسأله عن أوبس، فقال: تركته رث البيت قليل المتاع. قال: سمعت رسول الله صلى الله عليه وسلم يقول: يأتي عليكم أوبس بن عامر مع أمداد من أهل اليمن من مراد ثم من قرن كان به برص فبرأ منه إلا موضع درهم له والدة هو بها بر لو أقسم على الله لأبره، فإن استطعت أن يستغفر لك فافعل، فأتى أوبس فقال: استغفر لي. قال: أنت أحدث عهداً بسفر صالح فاستغفر لي قال لي: لقيت عمر؟ قال: نعم، فاستغفر له، ففطن له الناس فانطلق على وجهه، ثم غزا بأذربيجان، فمات بها.

## الرجل المجهول

► قال رسول الله صلى الله عليه وسلم ( طوبى لعبدٍ أخذ بعنان فرسه في سبيل الله، أشعث رأسه، مغبرة قدماه، إن كان في الحراسة كان في الحراسة، وإن كان في الساقية كان في الساقية، إن استأذن لم يؤذن له، وإن شفع لم يشفع ) رواه البخاري. وقال رسول الله صلى الله عليه وسلم (إن الله يحب العبد التقي الغني الخفي) رواه مسلم. وجاء في حديث معاذ (إن خير عباد الله الذين إذا غابوا لم يفتقدوا وإذا حضروا لم يفتن لهم يخرجون من كل غبراء مظلمة) رواه ابن ماجه. وروي في الأثر: ( إن أهل الجنة كل أشعث أغبر ذي طمرين لا يؤبه له، الذين إذا استأذنوا على الأمراء لم يؤذن لهم، وإذا خطبوا النساء لم ينكحوا، وإذا قالوا لم ينصت لهم. حوائج أحدهم تتخلل في صدره، لو قسم نوره يوم القيامة على الناس لوسعهم).

► قاتل رجل في أحد الغزوات في عهد عمر فأبلى بلاء حسنا وقتل فسأل عنه عمر فلم يعرفه فقال عمر: " ما يضره ألا يعرفه عمر ويعرفه رب عمر"