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# Understanding the Palliative Care Needs of Older Adults & Their Family Caregivers

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# Objectives

- Describe the unique needs of older adults as they approach the end of life;
  - Examine family caregivers' perceptions of the strengths and weaknesses in palliative care delivery in PCHs;
  - Explore areas of care delivery that significantly impact family caregiver satisfaction with end-of-life care.
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# Palliative Care for Older Adults

- Aging offers profound life changes.
- Death & dying are experienced in relation to life as a whole.
- Impact of losses and transitions on sense of purpose, meaning, & quality of life.

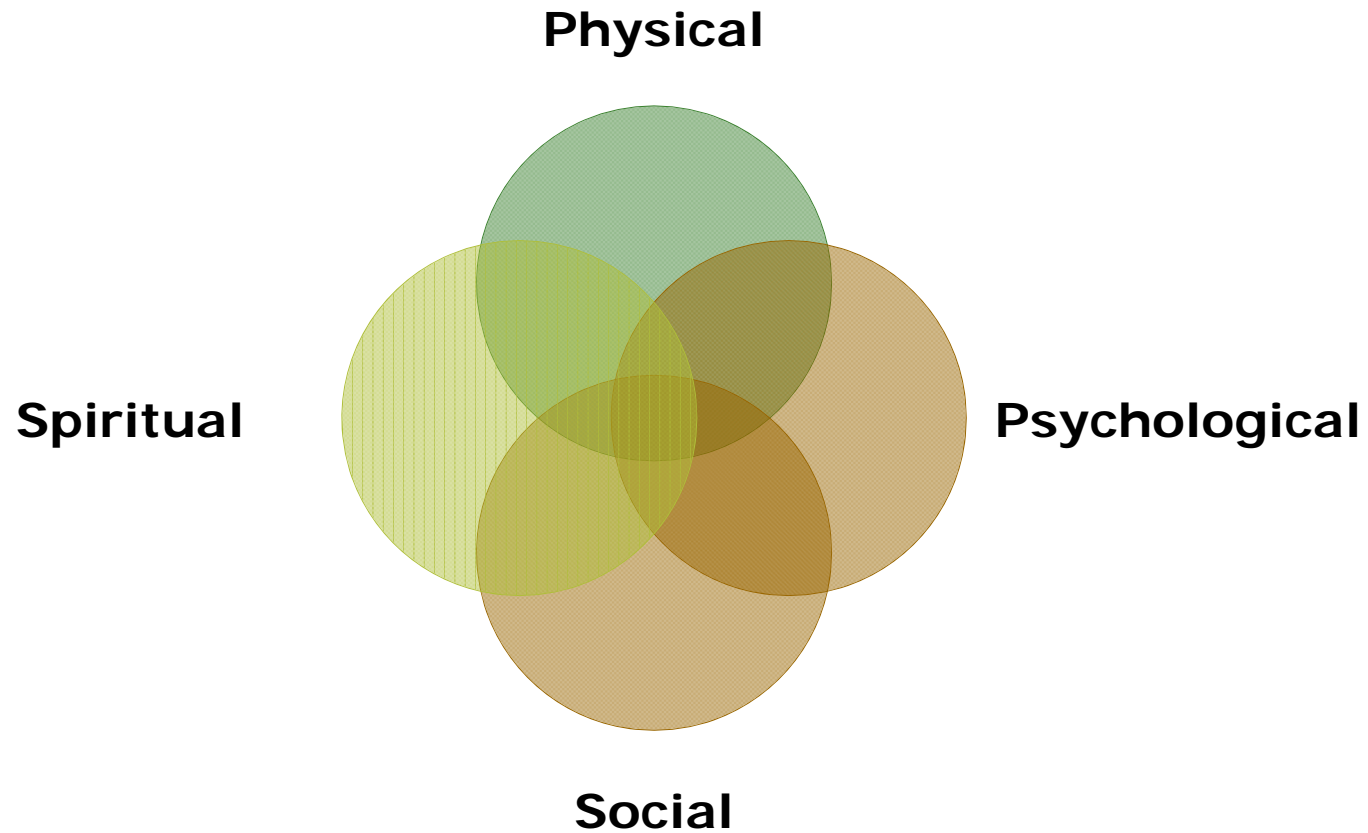


Photo: [www.hms.harvard.edu/cdi/pallcare/](http://www.hms.harvard.edu/cdi/pallcare/)

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# Domains of Care



Ferrell and Coyle (2008)

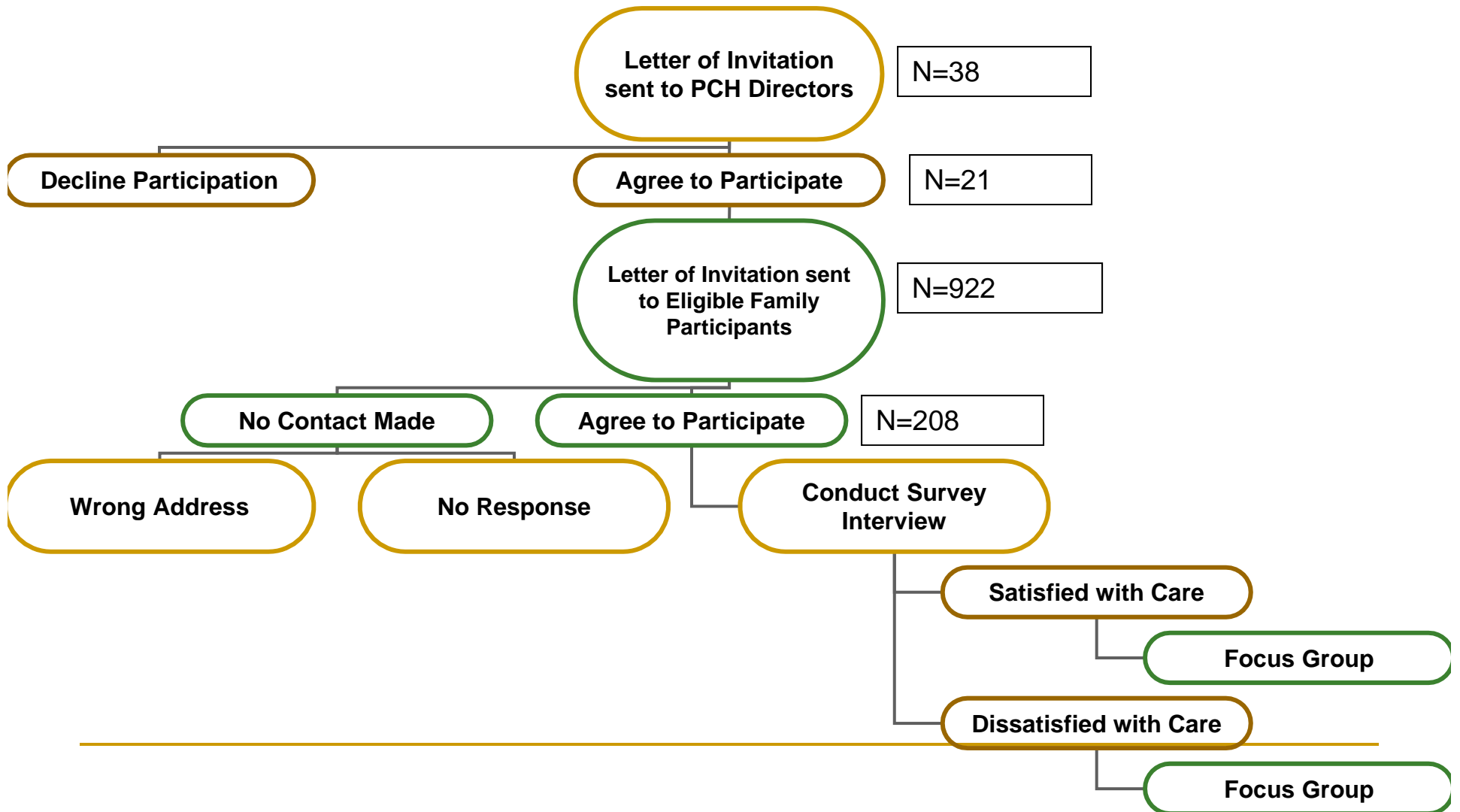
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# Research Questions

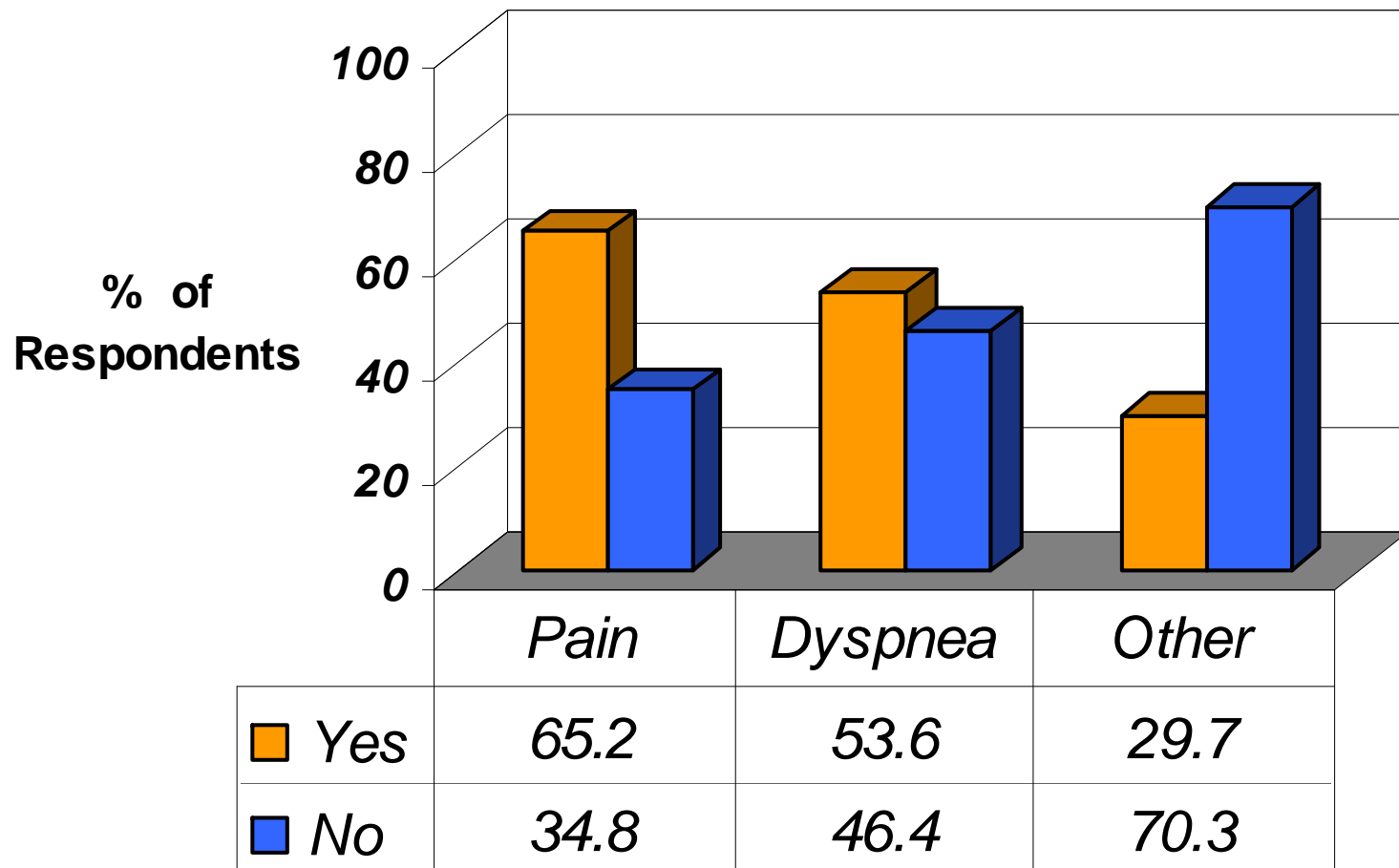
1. What are family members' perceptions of the quality of end-of-life care and their satisfaction with end-of-life care in the LTC setting?
  2. What are the associations between resident and family characteristics, systems characteristics, quality of care and family satisfaction with end-of-life care?
  3. What do family members identify as areas for improvement in the quality of end-of-life care provided in LTC facilities?
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# Research Study Protocol



	<b>Decedent (N=208)</b>	<b>%</b>	<b>Family Member (N=208)</b>	<b>%</b>
<b>Age (years), mean</b>	<b>87.5</b>		<b>62.5</b>	
<b>% Female</b>		<b>59.6</b>		<b>70.2</b>
<b>Diagnosis of dementia</b>	<b>121</b>	<b>58.5</b>	<b>N/A</b>	
<b>Residents with 6 or more medical conditions</b>	<b>133</b>	<b>63.9</b>	<b>N/A</b>	
<b>Relationship to decedent</b>			<b>25</b>	<b>12</b>
<b>Spouse/partner</b>				
<b>Adult Child</b>			<b>157</b>	<b>75.5</b>
<b>Sibling</b>			<b>10</b>	<b>4.8</b>
<b>Other</b>			<b>16</b>	<b>7.7</b>
<b>Visitation</b>	<b>N/A</b>		<b>73</b>	<b>35.3</b>
<b>Daily</b>				
<b>2 to 5 times a week</b>			<b>92</b>	<b>44.5</b>
<b>Other</b>			<b>42</b>	<b>20.3</b>

# Physical Well-Being





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# Physical Well-Being

- 26% identified that the resident received less pain medication than needed.
  - One barrier to pain management identified by participants was the manner in which medications were ordered.
    - Inconsistency in delivery and contradictory information between staff.
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After family members had visited they started Morphine in the evening to treat pain/ discomfort. She had been calling out, and her breathing was difficult. They increased the dosage and frequency over the next couple of days as appropriate. Her breathing changed with long periods up to thirty-eight seconds when she wasn't breathing. Staff told family that they couldn't give Morphine more frequently than every two hours unless she was taking at least ten breaths a minute. But it seemed my mother was very uncomfortable. She began calling out again. Doctor came and said they couldn't give the Morphine more often and didn't offer any alternative. Then in the last three hours of her life, the doctor said it was okay to give the Morphine more frequently.

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# Physical Well-Being

- 26% identified that the resident received less pain medication than needed.
  - Receiving less help than needed for breathing difficulties and emotional issues also reported as unmet needs by a small subset of respondents.
  - Adequate staff important – 28.2% reported not enough available to meet resident personal care needs.
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# Psychological Well-Being

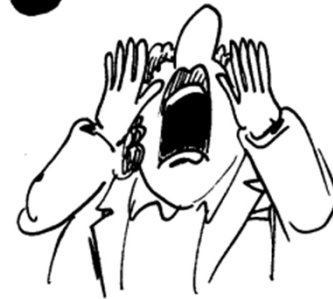
- Few respondents (27%) reported the resident had problems with feelings of Anxiety or Sadness.
  - 33% responded that more help could have been provided to resident to deal with those feelings.
  - Most felt the resident had been treated with Respect (78%) and Kindness (79%).
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# Social Well-Being

- One of the most frequently cited “other” symptom
  - Loneliness
- Need to remain engaged and to feel useful
- Important role for volunteers

**Volunteers!**

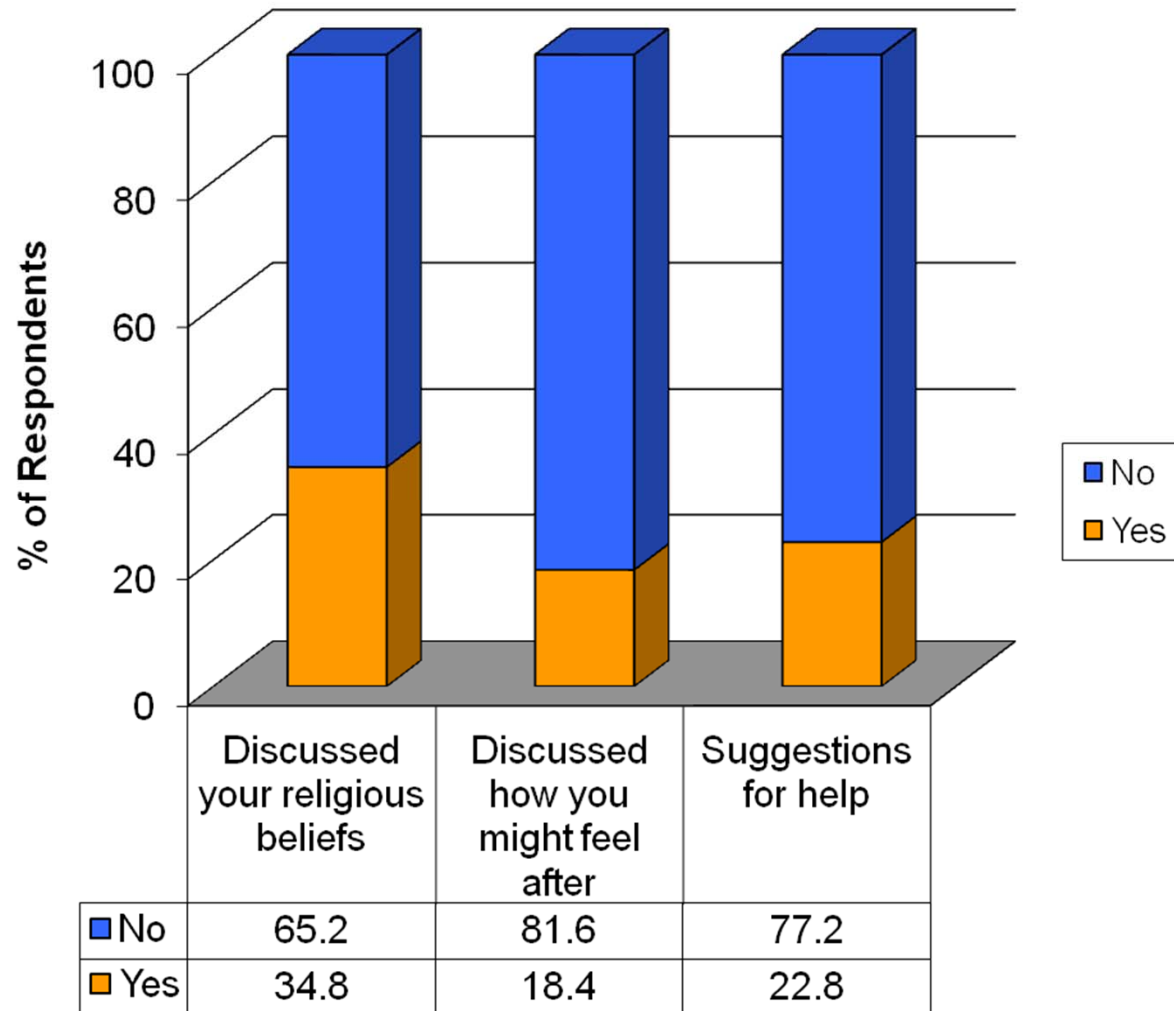


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# Spiritual Well-Being

- Feeling emotionally supported is a significant part of family satisfaction.
  - Few respondents reported receiving information on how they might feel after the death of the resident.
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# Spiritual, Psychosocial & Bereavement Support



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# Spiritual Well-Being

- Feeling emotionally supported is a significant part of family satisfaction.
  - Few respondents reported receiving information on how they might feel after the death of the resident.
  - Bereavement support highly variable.
  - Follow-up contact highly valued by family members.
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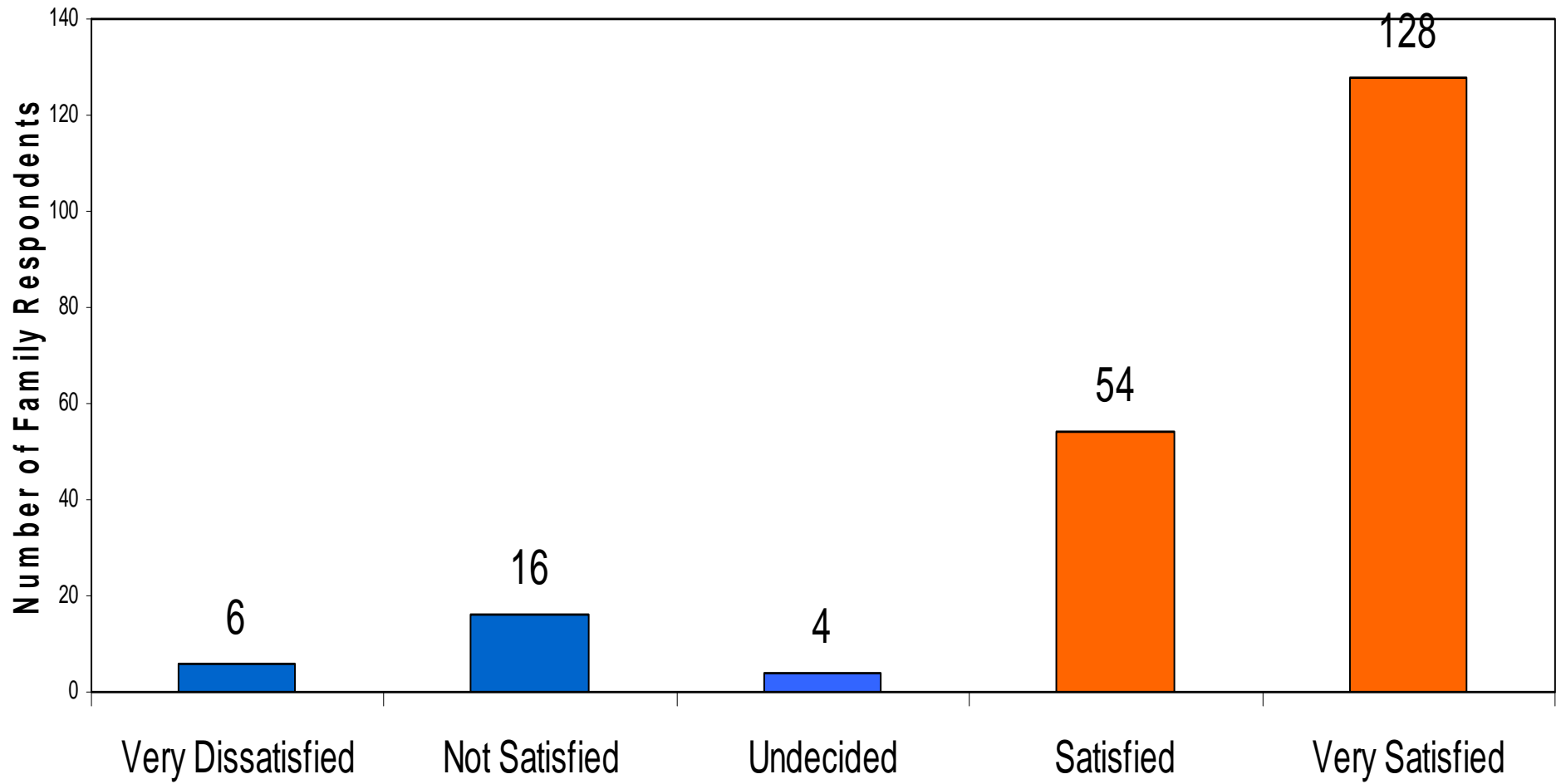
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# Family Satisfaction with Care

- Families play an important role as caregivers and serve as formal and informal proxy decision makers;
- Families are recipients of care and who have their own unique perspectives on the care delivered;
- Some preliminary evidence suggests when families care needs are met they are more satisfied;



## Satisfaction Ratings



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# Family Satisfaction with Care

Variability in family dissatisfaction attributable to:

- ❑ Communication with nursing staff
    - Received less information than needed
    - Received confusing information
  - ❑ Care failed to meet expectations
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## 1. Communication – Confusing Information

- Family members who stated they had been provided with confusing information regarding the care or treatment of the resident from nursing staff were 6 times more likely to be dissatisfied with the care provided at the end of life.
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# Confusing Information

- 16.6% of respondents reported the problem of receiving confusing or contradictory information from nursing staff.
  - Dissatisfied family members significantly more likely to report this as an unmet need than those who were satisfied with care (58.3% versus 10.9%).
  - 12.5% of all respondents also felt that the health care aides gave confusing information.
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## 2. Communication – Inadequate Information

- Family members who identified receiving less information than needed regarding the medical condition of the resident from nursing staff were **7** times more likely to be dissatisfied with end-of-life care.
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# Inadequate Information

- Reported as an unmet need by 17.2% of family members.
  - Dissatisfied family members were significantly more likely to report this as a problem than those who were satisfied (60% versus 11%).
  - 30% of respondents reported wanting more information about what to expect during dying and did not feel they were always kept informed about the resident's condition.
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There's one time when I look back on my mom's life, where she probably would have died at that point had I not taken her into the hospital and it would have been nice if someone would have been there to coach me or tell me things or explain things to me because with what happened in the hospital at this point I never would have taken her...telling me that the things my mother was going through was actually that she was dying.

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## Communication & Interaction with Care Providers

- Importance of involving families in decision-making.
  - Communication around what to expect at the end of life;
    - Sharing of information in a timely, sensitive manner
  - Providing emotional support to families;
  - Compassionate, humanistic behaviors play a key role.
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...when she [mother] was going through her dying process, people would come in and they would sit with me and they would talk with me and that was the hairdresser, that was the lady who brought the dogs, and you know, so it wasn't just the nursing staff... it was wonderful for the family to have someone show us that kindness.

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## 3. Expectations

- Family members who felt the care failed to meet their expectations were almost 39 times more likely to be dissatisfied with care at the end of life.
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- When asked “Did the care the resident received in the last week/month of their life meet your expectations?”, family members replied:
    - No (17.8%)
    - Yes (79.3%)
    - Don't Know (2.9%)
  
  - Of those who were dissatisfied, 73.1% reported that care had NOT met expectations versus 10.2% of those who were satisfied with the care.
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# Consequences of Dissatisfaction

- Strong sense of regret, anger, frustration, sadness, unmet needs, and that they had let the resident down.
  - Feeling that they “needed to be there all the time to ensure that things got done”.
  - Wanting to distance themselves from the facility.
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I had this sense, of not failure, but I didn't deliver what I promised her because we had this conversation [about being pain free], and I promised her and there's the huge sense that I let her down and I hate that; I think I'll always feel regret for what happened in that week.

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# Implications

- As much of family satisfaction with care revolves around the importance of provider communication, LTC facilities may want to focus on:
    - Educational opportunities for staff;
    - Exploring ways to identify family member expectations regarding care at the end of life;
    - Discussing with residents their goals of care and expectations regarding the care they wish to receive in their final days.
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I think most people [who] go there [PCH], eventually pass away...I'm amazed that the death word is not part of their business. Funeral homes don't mind talking about death. There are acknowledged segments of society who are in the business of giving people the best service as part of this process, why can't that be something they're equally proud of as their hot meals.

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