Consumer and Patient Reactions to Trials of Chemotherapy Reductions
Reveal an Urgent Need to Name and Explain the Concept

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Background
- Trials involving reductions in cancer treatment, particularly chemotherapy, are a growing trend
- The hope is that eliminating/reducing drug(s) will reduce toxicity burden and increase QOL without increasing recurrence or death
- Large well-designed clinical trials are needed to ensure the hope becomes a reality

Objective
- Understand consumer perceptions to inform design and communications that enhance accrual

Methodology
Qualitative study including 5 online focus groups, in April/May 2020 (after COVID pandemic began)
- 2 with patients: to draw on experience; identified and recruited via Living Beyond Breast Cancer (diagnosed with HER2+ breast cancer 3-5 years ago)
- 3 with consumers: who had never had cancer, identified via nationwide market research panel
  - Provide “cancer-naïve” perspective that may more closely match that of newly diagnosed patients
  - Inform understanding of public opinion, potentially a key in acceptance of reduced treatment

Results
1. Initial reactions were not particularly positive or negative; Questions are to be expected and oncologist recommendation is essential
   - Reasoning and rationale
   - Timeline
   - Details of each part of therapy, particularly what might be avoided
2. Motivations aligned with trial goals
   - Avoiding some chemotherapy
   - Taking only what is needed
3. Concerns were significant
   - Lengthening duration of treatment: Participants perceived that the path with additional chemotherapy would translate to more months of treatment, a significant barrier to interest
     - Fear: The results are unknown; some need to feel they have done “everything” to avoid decision regret
     - Cost: Potential for more visits and time out of work represents significant cost, even if treatment covered
4. Language reactions and discussion favored focus on the positive aspects of reduced treatment
   - Positive reactions to: lighter, milder, more manageable, less invasive, minimal
   - Strong negative reactions to de-escalation (military connotations)
   - Some negative reactions to toxicity (unfamiliar and frightening)

Discussion
- Patient reactions suggest communication approaches are needed to enhance accrual
  - Find a term to replace de-escalation
  - Employ appropriate descriptions of possible upsides: take only what is needed; possibly reduce side effects, costs, and time burden
  - Address concerns to the degree possible:
    - Can duration issue be mitigated if longer path is seen as “only traveled if needed”?
    - Can fears be addressed with open conversation and psycho-social support?
    - Perhaps fear of “taking less” can be reduced by addressing “more is always better” attitudes/norms at broader/societal level
- Oncologist recommendation is key; therefore, they need to be equipped with language and tools to provide rationale, address questions, and communicate as effectively as possible

Future Directions
- Conduct a survey with patients and consumers to quantify these small sample findings
- Develop descriptions of trials that employ patient-centered language
- Provide oncologists with language and tools

Limitations
- Focus group format provides qualitative input and participants may be influenced by one another, always involved single extraction of themes by research team
- Total sample included only 30 people

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