"THAT'S LIFE" (WITH HEMOPHILIA): A QUALITATIVE ANALYSIS OF YOUNG MEN'S EXPERIENCES OF CHANGE

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BACKGROUND

- Health care professionals often focus on the clinical changes in patients with hemophilia to guide treatment planning. However, social changes may also impact their health related quality of life (HRQoL).
- The term HRQoL was introduced in medicine because of the concern that the global concept of quality of life (QoL) may not be affected by health care interventions (Guyatt & Cook, 1994).
- HRQoL is influenced not only by a disease and its treatment, but also by personal characteristics, by living conditions and by socioeconomic status (Von Mackensen, 2007).
- According to Eiser and Morse (2001), subjectivity is the key to measuring HRQoL.
- Literature in the field of hemophilia is dominated by quantitative studies on bleeds, joint damage and clinical treatment (Leissinger, 2004; Hilliard et al., 2006; Manco-Johnson & al., 2007).
- There is a lack of qualitative research examining social factors that could potentially have an impact on the HRQoL of patients with hemophilia. Therefore, further qualitative research is required to examine the non-clinical factors that may impact HRQoL outcomes.

OBJECTIVES

1) To provide a detailed description, from a qualitative approach, of life experiences that are perceived to be important by young males with hemophilia
2) To determine the (positive or negative) impact of social changes on the perceived overall HRQoL of young males with hemophilia
3) To inform health care providers about the potential impact of social changes when assessing the HRQoL of patients with hemophilia

METHODS

Participants: 30 Francophone males, 15 to 29 years of age with moderate to severe hemophilia, recruited from 4 Canadian hospitals as part of a larger Canadian study

Data Collection: Semi-structured interviews investigating changes in participants' lives over the past 2 to 3 years were conducted

Interview Process:
1) Demographic information was collected at baseline, along with the participants' perceived important life experiences (i.e. severity of hemophilia, occupation and relationship status). The participants were asked to qualify the changes as a small/big and positive/negative impact
2) Participants were asked if they had experienced other important life events since their enrollment in the study. The interviewer asked the participants if the important changes they reported on previous surveys (collected at 6 month intervals) still had the same impact on their lives
3) Emphasis on understanding the events that impacted the participants' HRQoL since the beginning of the study. They were also asked to qualify their HRQoL as much improved, improved, no significant change, deteriorated or much deteriorated

Data Analysis: The interviews were transcribed, imported into the NVivo software to facilitate qualitative analysis, and submitted to a thematic analysis

RESULTS

Sample:
- 6 youth (mean age = 16.4, range = 15 to 18 years)
- 24 adults (mean age = 24.4, range = 20 to 29 years)
- 7% moderate and 93% severe hemophilia

3 Main Themes emerged that were evident in both youth and adults (total sample of 30 individuals).
- Work/Financial Stability (identified in **54** quotes from **29** individuals)
- Relationships/Family (identified in **55** quotes from **24** individuals)
- Counter-Balance (identified in **32** quotes from **16** individuals)

Work/Financial Stability

- Most important theme because of the overall impact on the participants' perceived HRQoL
- Importance of the participants' types of work (e.g., mechanic vs. manager)
  - Having a physically demanding job "all my life" worried some participants because they are not "Superman"
- Participants related financial stability to success
- Youth felt independent when beginning their first job
- Education was important because it allowed participants to have a job in their desired field
  - "It's important because I'm choosing my career."

In the following tables, sub-themes are listed in decreasing order of meaning/mentions. The number in parenthesis refers to the number of participants who brought up this sub-theme in the interview.

Positive	Negative
New job (17 participants)	Physically demanding jobs (6)
Change of responsibility/promotion (11)	Stress associated with work and finances (3)
Financial stability (9)	Less hours/layoff (3)
Increase in finances (6)	
Job in their field (5)	

Relationships/Family

- Relationships were usually the first important life experience the participants mentioned
- Major impact on perceived happiness (i.e. one participant stated being in a relationship helped him "feel good" everyday)
- When break-ups/separations/divorces first occurred, the participants felt "down"
- Eventually, participants stated that "…it had a big impact but [I] see it as positive, not negative."
  - The participants valued the resulting personal growth from break-ups/separations/divorces
- Family was a more important theme for youth (due to the fact that most of them lived with their parents/family members)

Positive	Negative
Learning from mistakes (8)	Break-up/separation/divorce* (9)
Moving-in with partner (6)	Death/illness of family member (6)
Stable relationship (6)	
Moving from parents' house (4)	
Marriage (3)	

* For most participants, break-ups/separations/divorces turned into positives

Counter-Balance

- Life-events were only indirectly linked to hemophilia, which was not mentioned often by participants
- Participants appeared to "counter-balance" the impact of their illness by focusing on the positive elements in their lives (i.e. experiencing more bleeds but having a new relationship)
- Participants considered their symptoms "part of life"
  - "I learned to work with the body that I have…"
- 26 of 30 participants reported a stable or an increase in their overall HRQoL
- Only 16 of 30 participants mentioned hemophilia
- Increase in HRQoL was usually tied to work, financial stability, health or relationships

Positive	Negative
Stability related to illness (10)	Injuries and bleeds (8)
More mobility (8)	Less mobility and more weakness (6)
Treatments (7)	Difficulties with work (5)
Decrease in bleeds (4)	Thinking of future (5)
Participation in regular activities (3)	Decrease in health (4)

CONCLUSIONS

- Participants seemed to attach greater importance to the social changes in their lives as opposed to the clinical changes
- Hemophilia seemed to only be mentioned as the participants described their overall HRQoL
  - The knowledge that they were part of a hemophilia study may have influenced the participants to mention their illness
- To improve patients' overall HRQoL, health care professionals need to consider important social changes when assessing changes over time and the effect of interventions

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